

**AN EVALUATION OF THE
SACLA REHABILITATION WORKER
PROJECT IN CAPE TOWN,
SOUTH AFRICA.
1992-1993.**

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University of Cape Town

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ABSTRACT

This dissertation reports on an evaluation of the home visiting programme of the SACLA Rehabilitation Worker project against the background of the socio-economic context of the community and the history of the project. The evaluation had two aims. Firstly it aimed to highlight the programme's strengths and weaknesses so that the work could become both more efficient and more effective. Secondly, it aimed to establish whether the SACLA rehabilitation project is an effective model of a community based rehabilitation project on which other local projects could be based. Quantitative data was collected by interviewing the caregivers of disabled children who were involved in the project. In-depth interviews with the rehabilitation workers provided qualitative data which was used to confirm the validity of some of the quantitative data. The foremost findings were that the mothers were very positive about the support received from the RWs. The majority of the caregivers remembered the activities that they had been taught by the RWs and performed them well. Poor communication with the caregivers and a lack of skills on the part of the RWs gave rise to a number of problems. A number of changes highlighted by the evaluation were suggested. In conclusion, the project was found to be an effective model of local community based rehabilitation on which other projects could be based.

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**This work is dedicated to the disabled children
and their caregivers with whom we work
in the townships of the Western Cape.**

ABBREVIATIONS USED IN THIS DISSERTATION.

| | |
|--------------------|---|
| A.P.S. | - Average Performance Score |
| ANC | - African National Congress |
| C.P.A. | - Cape Provincial Administration |
| CBR | - Community Based Rehabilitation |
| CERSA | - Centre for Epidemiological Research in South Africa |
| CGS | - Caregivers |
| CHW | - Community Health Worker |
| DPSA | - Disabled People South Africa |
| IBR | - Institution Based Rehabilitation |
| NGO | - non-governmental organization |
| Not signif. | - not significant |
| n/s | - not significant |
| RW | - Rehabilitation Worker |
| S.A.D.F. | - South African Defence Force |
| S.A.N.C.O. | - South African National Civic Organization |
| SACLA | - The name of the non-governmental health organization of which the RW project forms a part. The name came initially from a conference named the South African Christian Leadership Assembly (SACLA). |
| UNDP | - United Nations Development Programme |
| W.C.R.S.C. | - Western Cape Regional Services Council |
| WHO | - World Health Organization |

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CHAPTER ONE: THE SOCIAL CONTEXT.

In order to better understand the context in which the SACLA Rehabilitation Worker (RW) project operates, and the wider background to the evaluation of that work in this thesis, the social conditions that prevail in the townships in which the SACLA RW works are examined in this first chapter.

By describing the geography, socio-economic issues, and traditional beliefs, the context of the RW project will be discussed. Given the focus of this thesis, it is understood that this chapter will only provide the bare outlines to what is clearly a huge undertaking in its own right.

1.1. DEMOGRAPHY AND HEALTH SERVICE PROVIDERS IN THE DIFFERENT TOWNSHIPS.

The SACLA RW Project operates in a number of different townships in the Western Cape including New Crossroads, KTC, Brown's Farm, Millers Camp and Site B, Site C and Makaza areas of Khayelitsha (see map: Appendix A). The conditions that prevail in these townships and the general health services provided will be discussed in this section (see map: Appendix B). Information is hard to come by, and even organizations working in the area do not have adequate statistics.¹

A. *Site B*: This area of Khayelitsha was established in 1985 and 1986 to address the squatter problem in Cape Town. In 1992 it was estimated to have a population of 95,141.² Most people live in shacks in a "site and service" scheme which means roads are graded and plots laid out in a systematic way with an outside flush toilet and an outside tap for two shacks. However, a number of people live in temporary areas where there are no toilets or taps.² Preventative health services are provided by the Western Cape Regional Services Council (W.C.R.S.C.) clinic. The Cape Provincial Administration (C.P.A.) runs a Day Hospital which provides curative services and a maternity unit run by midwives.

B. *Site C*: This area of Khayelitsha was also established in 1985 and 1986 to address the squatter problem in Cape Town. In 1992 it was estimated to have a population of 67,517,³ all living in randomly situated wood and iron shacks. Water is provided by communal taps and sewage buckets are collected twice a week. Preventative and curative health services are provided by the Nolungile clinic. At the Nolungile clinic the C.P.A. and the W.C.R.S.C. are working together to provide an integrated health service.

C. *Makaza*: This area of Khayelitsha is also known as Mayibuye. In 1991 it was estimated to have a population of 26,438.⁴ It is a "site and service" area with people living in shacks with an outside tap and flush toilet for each plot. There are no preventative or curative health services in the area. People go to the Site B health service complex for health care, which is described above.

D. KTC: This has been a squatter camp for many years. Since 1975 it has grown slowly. In 1991 it was estimated that the population of KTC was 30,000.⁵ Until recently it was a shack area serviced by communal taps and buckets for sewage, which were collected twice a week. At the moment part of the area has been upgraded to a "site and service" scheme. There are no health services in the area. For preventative services people use the Nyanga clinic which is run by the W.C.R.S.C. People attend Guguletu day hospital (C.P.A.) if in need of curative services.

E. Millers Camp: This area developed as a refugee community in 1986 when people fled from the "witdoek" conflict in Old Crossroads. In mid 1991 it was estimated that the population of Millers Camp was 12,000 people.⁵ However the community is in flux at the moment as the area is being upgraded to a "site and service" scheme. There will be room for 2250 people in the new upgraded Millers Camp, so the remaining 9750 people have to find another place to live. Already a number of people have moved to Brown's farm. No health services are provided in the area, people go to the Nyanga clinic (W.C.R.S.C.) for preventative services and the Guguletu day hospital (C.P.A.) provides curative services.

F. Brown's Farm: This is a fairly new "site and service" area, with people living in shacks. There are 25,000 people living in the area, 10,500 in the new area called Zinyoka meaning "The place of snakes." Each plot, designed for one house, is provided with an outside tap and toilet. No preventative or curative services are provided in the area. The people go to the Guguletu day hospital (C.P.A.) and Nyanga clinic (W.C.R.S.C.) for health services.

G. New Crossroads: New Crossroads was established in 1982 as phase 1 of plans to house squatters from Old Crossroads. People live in brick houses which have an inside tap and flush toilet. In 1990 the population of New Crossroads was said to be 10,000.⁶ There are no health services in the area. For preventative health services people go to Nyanga clinic (W.C.R.S.C.) and for curative services they go to the Guguletu day hospital (C.P.A.).

1.2. SOCIO-ECONOMIC CHARACTERISTICS.

There is a considerable amount of information about socio-economic characteristics for Khayelitsha and relatively little about the other areas in which the SACLA RW project works. In this next section we will be looking at information concerning Khayelitsha. However the other areas are similar with respect to the characteristics mentioned below.

1.2.1. Patterns of Movement.

The vast majority of people in Khayelitsha come originally from the so-called independent homelands of the Transkei and Ciskei. Cooper et. al.⁷ noted that 47,5% of the women in Khayelitsha had migrated to an urban area in the last five years. Economic and familial factors constitute the two primary reasons for this migration to Cape Town.

Joseph Gugler has noted that this is a pattern common throughout the third world:

In Africa and Asia migrants are sent to the city so that the family in the rural area can enjoy a stream of remittances that will enhance their living standards.⁸

A pattern of movement that was noticed in the squatter camp of Crossroads was that children were sent back to the Transkei and Ciskei to ensure a secure rural base in case the family were evicted, became unemployed or needed to secure a Transkei pension.⁹ This relative absence of children has also been noted in Khayelitsha where they are sent to the Transkei and Ciskei for childcare and schooling.⁷

Not only is there a migratory pattern of movement to and from the Transkei and Ciskei, but within the squatter areas themselves there is sustained movement.

People move from unserviced to serviced areas, from violent to less turbulent areas and from flooded to drier areas. Movement is greatest during the rainy months and periods of political upheaval.²

1.2.2. Unemployment.

The vast majority of people in Khayelitsha have no formal employment skills. In the shack areas nine out of ten people are unskilled. "It is a bit like a social sink, where the poorest individuals, particularly single women end up."⁷

In 1988 half the adult population were unemployed. Far more men (75%) than women (32%) were employed.¹⁰ 90% of the women employed earn less than the Minimum Living Level of R570,81 a month.⁷ The le Roux's showed that in Site B, one fifth of the households had no wage earners at all.¹⁰

In response to this poverty, women in particular work informally performing a number of activities, for example hawking food, working in shops, working in shebeens and doing handicrafts. Households take in non-family members as lodgers who then pay rent to the house owner. Many houses use the income of one individual within the house

for example a disability grant or old age pension, not only to survive, but to send children to school.¹¹

Employment is linked to the number of years people have spent in an urban area and the number of years of formal schooling they have had.⁷

1.2.3. Literacy, Education and Language.

Less than half the children of primary school age in Khayelitsha are enrolled at school, and while one in twelve adults in Khayelitsha has had no formal education half of the population has no secondary education.²

There are a number of primary and secondary schools in the area. Many of them have two shifts, so that some children go to school in the morning and some in the afternoon. However, the classrooms are still overcrowded, books scarce and the morale of the teachers low. This creates a tension for many families as they value education highly, but the education system undermines their attempts to keep their children at school.

The le Roux's assumed functional literacy after four years at school and they found that 76% of the population were functionally literate.¹⁰ The people living in these areas are all Xhosa speaking, only a few are able to speak English.

1.2.4. Biophysical Environment.

Joseph Gugler notes the following with respect to biophysical environments in the Third World:

World wide the poor live on the worst land in terms of inherent characteristics, areas most liable to flooding, areas subject to subsidence, poorest soils and also the worst land in terms of acquired characteristics, worst pollution, least services, worst transportation.⁸

The areas in which the SACLA RW project works are no exception, being built on the Cape Flats. The nature of the Cape Flats affects communities in three ways. Firstly, the soil is of a low agricultural potential, so people cannot grow much produce. Secondly, the water table is high so that flooding in the winter is common. Thirdly, strong winds blow over the sand, wearing structures down, penetrating the smallest holes and subjecting people to gritty discomfort, which makes for very tiring living conditions.

1.2.5. Local Administration and Politics.

Cole¹² has indicated how power struggles and inter-group rivalry were prominent features of local political life in the Crossroads squatter camp outside Cape Town. This continues to be true in the townships and squatter camps in which the SACLA RW project is based. The people in power at any particular time are constantly trying to co-opt squatters onto their side to reinforce and extend the legitimacy of their regime, although in reality this provides no access to real or institutionalized power. "The poor do not have power itself, just the symbols of power."⁸

Initially all the squatter areas were controlled by headmen, a legacy inherited from the rural areas. At the moment however, civics affiliated to a strong, progressive, anti-apartheid national civic organization the South African National Civic Organization (S.A.N.C.O.)¹³ are in the seats of power in most of the townships in which the RW project operates.

A. Khayelitsha (Site B, Site C and Makaza). The local authority responsible for Khayelitsha is the Lingelethu West City Council. Initially local headmen controlled the area of Site B and community councillors were in power in Site C. During the period under review civics control Site B and Makaza. In Site C there is a power conflict between the civics and the mayor with his community councillors.

B. KTC and New Crossroads. Local administration is in the hands of the EKAPA Town Council. The Council comprises Cape Provincial Administration (C.P.A.) officials and community councillors. In all the areas the community councillors have resigned leaving the C.P.A. officials in charge. Local power is in the control of civics.

C. Millers Camp and Brown's Farm. Two head men control both of these areas, Mr. Sphika and Mr. Yamile. Millers Camp is administered by the EKAPA Town council and Brown's Farm (as it is on the other side of Lansdowne Road) by the C.P.A. which sub-contracts much of this work to the EKAPA Town Council.

1.2.6. Non-Governmental Organizations. (NGOs)

Due to the fact that these townships are close to a big urban centre where there are a lot of resources, there are at least 20 different NGOs operating in Khayelitsha. These NGOs provide resources and employment which are important for people in the area. However, problems do arise. For example there are a number of different nutrition centres in Khayelitsha. It is recognized by the nutrition workers running these centres that the mothers "shop around" going

from one to the other, to see which offer them the best deal. Much work is needed to prevent the duplication, confusion and tension that arises.

1.2.7. National Politics.

Life in a squatter camp is dominated by the local socio-economic conditions as described above. Nevertheless the national political situation has an all pervasive influence upon these social conditions.

Newspaper reports during the period reviewed by this evaluation (1988 to 1993) make clear that the political environment in South Africa has been characterized by uncertainty and disruption.¹⁴ Prior to the unbanning of the ANC and other liberation movements, the townships and squatter areas were under siege from the security forces, while popular movements sought to make them ungovernable. Basic social needs such as education, housing and health care were in a state of crisis characterized by boycotts, strikes and the unavailability of government funds. Rhetoric was characterized by utopian hopes of speedy and full liberation.

Since February 1990, the situation has not improved for the average person living in the townships and squatter camps. Hopes of simple equality and the adequate provision of social needs have dimmed and in their place is the grim determination to survive the wave of violence that has accompanied this period of negotiations at a national level for a "new" South Africa.

There is a growing realization by most political groupings in the country that unless the political impasse regarding a democratic constitution and election is overcome, and the struggling national

economy begins to show signs of stability and growth, the future holds little promise for a better life for people living in the townships and squatter camps.

1.2.8. Violence.

As with so many other urban and peri-urban areas in South Africa, violence is endemic at a number of different levels in these townships. Although there are no figures to measure accurately the magnitude of domestic violence it is clear that child abuse, rape and wife beating are common and go largely unchallenged.¹⁵

The level of criminal violence is also very high. Newspaper reports indicate that much of it is due to gangsterism, political rivalry and possible security force involvement (the so called third force).¹⁴

1.2.9. Disability.

The WHO has estimated that the number of disabled people in a community is 7% -10%, and in less developed countries it is nearer 10%.¹⁶ Recently, however, these figures have been disputed and a figure of 4.5% for less developed regions has been proposed.¹⁷ As Khayelitsha is typical of a less developed region it can be assumed that between 4.5% and 10% of the population is disabled.

A recent report by the SACLA rehabilitation project¹⁸ which covers approximately 5% of the disabled people living in the squatter areas of Khayelitsha indicates that children comprise 59% of the disabled population. The dominant condition seen in children is neurological (78%) of which cerebral palsy comprises 82%. Other

significant conditions seen in children are orthopaedic problems (10%) and mental handicap (6%).

The most common condition seen in adults is also neurological (67%) of which cerebral palsy comprises 28% and cerebral vascular accidents 25%. Other significant conditions seen in adults are orthopaedic (23%) and mental handicap (5%). The report indicates that within the squatter areas of Khayelitsha the most common form of disability is cerebral palsy in children (38% of all cases).

1.3. TRADITIONAL BELIEF SYSTEMS.

Most people in the areas in which the RW project functions subscribe to traditional African belief systems, although this is becoming less and less meaningful as people spend longer in urban areas and aspire to Western aspirations and ways of living.

Vera Buhrman in *Living in Two Worlds* has identified two of the most important aspects of the Xhosa belief system. The first is the role of the unconscious. Xhosa people to a large extent are still in touch with the psyche and its symbols which have power and meaning for them. The second is the major role which the ancestors play in people's lives.

A symbiotic relationship seems to exist between the living and their ancestors, the role of each being to keep the other happy, healthy and viable. The constant remembrance by the living of the dead keeps the "living dead" alive, content and functioning.¹⁹

When a person becomes ill, home remedies are first tried. If these are not successful then either a Western trained doctor, a witchdoctor (*igqira*) or herbalist (*ixwhele*) will be consulted and often more than one.²⁰ Although they may have been in contact with Western medicine for a number of years, many people still have a

traditional understanding of disease and will try traditional remedies before they see a doctor. For example at SACLA, one of the most well known workers, who has worked for the organization for 12 years and now trains community health workers will still treat her own children with an enema (the traditional method of treating diarrhoea, to remove the evil spirit from the body) before she consults a doctor.

There are also many traditional beliefs about the causes of disability. To illustrate: In answer to the question asked in a training session as to the traditional causes of brain damage, manifesting in cerebral palsy and epilepsy, the following answers were given by mothers of disabled children:²¹

- * The *amafufunyana*, a particular spirit that has entered the person can lead to these problems.
- * A bad wind was blowing which affected the baby.
- * The mother had a vision and in the vision saw a snake or mermaid. As a result the baby is affected.
- * The mother had sex whilst she was still breast-feeding her baby, so the unborn foetus is damaged.

Furthermore, many of the disabled people seen by the RWs are epileptic. In the traditional belief system this is as a result of spirits or *amafufunyana*, which is treated by a witchdoctor. People are then reluctant to see a doctor or take the prescribed medicines.

1.4. CONCLUSION.

Disabled adults, and disabled children and their caregivers along with all people living in the townships and squatter camps face the conditions which have been described in this chapter. For these disabled people and their families however, their disability compounds the constant struggle to survive and live a stable life.

Any attempt by health service providers to meet the needs of the disabled in these communities must therefore take this context very seriously. This is the broader framework in which to understand the vision of the SACLA RW project.

CHAPTER TWO: THE SACLA REHABILITATION PROJECT

2.1. A HISTORY OF THE SACLA HEALTH PROJECT.

2.1.1. Introduction.

SACLA is a Christian, non-governmental organization involved with primary health care in the Black townships of the Western Cape. All except one of the areas of work are squatter communities. The work of SACLA started in 1980, and has undergone a number of changes since then.²²

These twelve years at SACLA may be characterized by four different periods. Under these four different periods the major themes that emerged during the time will be discussed.

2.1.2. Period One: A Curative Health Service (1980 - 1986).

In June 1979 a large Christian ecumenical conference, the South African Christian Leadership Assembly (SACLA), was held in Pretoria. The vision of this conference led to the establishment of the Empilisweni SACLA Clinic by Dr. Ivan Toms, Ms Thoko Mtulu and others, in the illegal squatter camp of Old Crossroads in 1980.

Curative care was provided to the community of Crossroads from this clinic, staffed mostly by white health professionals. By 1986 the clinic employed amongst others four full time doctors (who were seeing up to 200 patients a day) a primary health care nursing practitioner, a dentist and a physiotherapist.

The controlling body of the clinic was a committee on which local community people, church representatives and clinic staff ^{were represented.} Clinic

staff were responsible and accountable to this committee, and saw to the daily running of the clinic.

The state funded the salaries of the professional staff, as they were prepared to be involved in funding a curative service. However, this relationship with the state was precarious and SACLA's status had to be renegotiated with the state annually. Other funds came from local and international churches and agencies.

It was towards the end of this first period that the rehabilitation service at the clinic was initiated. The doctors and other members of staff who came across disabled people would refer them to the physiotherapist, who saw them either at the clinic, or in their homes. There were so many disabled children, that two days a week were set aside for children and their mothers only. Whilst the physiotherapist played with and treated their children, the mothers talked, sharing their common joys and sorrows. Although this started off as an informal group, it became a great support to the mothers who attended regularly.

The clinic had a high profile in the anti-apartheid activities of the early 1980s, enjoyed constant public interest and media attention and was regularly visited by important political and church people. Being a visible and obvious power base the clinic was drawn into local power struggles.

In 1986 the "witdoek" conflict erupted in Crossroads. This was a power struggle for leadership between the different headmen around whom the community was polarized. The South African Defence Force (S.A.D.F.) and Police became involved and due to the geographical position of the clinic the situation became unbearable and unsafe. In June 1986 the clinic was closed.

2.1.3. Period Two: A Transition Phase of Analysis and Assessment (Second half of 1986).

During the second half of 1986 the staff assessed and analyzed their work and planned a new direction for what became the SACLA Health Project.

The idea of a curative health care service was abandoned for a more holistic approach that included community development, preventative health care and curative health care. Rather than working from a fixed clinic building the plan was to work through local people who would be trained as Community Health Workers (CHWs) and would work from their homes.

State funding was stopped as soon as the service in Crossroads was stopped. Since this time the raising of funds has been a vital part of the work.

For protection from the State a relationship with the Anglican church was consolidated and Archbishop Desmond Tutu became the patron of the project. A controlling committee called the Central Committee was set up to have overall authority over the organization and to whom the staff would be accountable. The Anglican church was well represented on this committee though attempts to have community members on this committee were unsuccessful.

2.1.4. Period Three: Establishing A Primary Health Care Service (1987 - 1990).

During this period the plans developed during the transition period of analysis and assessment were implemented. The number of health professionals in the organization was considerably reduced and most of their time was spent developing training material, training people

from the community to be both Community Health Workers (CHWs) and Rehabilitation Workers (RWs) and supporting these workers.

The administrative centre was built close to the area of work, but specifically not within one particular community, to avoid being trapped by another conflict or the demands of only one community.

SACLA's relationship to different communities was mostly through the CHWs and RWs. Communities were not involved in the running of or the authority structures of SACLA and only consulted when either CHWs or RWS needed to be elected in an area. The project's vision and direction was planned by the staff who were accountable to the Central Committee. One of the major problems to emerge during this time was the issue of the accountability for the CHWs and RWs. The question was asked are these community based workers accountable to the Central Committee or to the community?

Funding during this time came from international funding agencies, American foundations and Overseas Church Organizations. There was no support from the state at all, and working alongside state structures was very frustrating, as they ignored the work and workers of SACLA (particularly the community based workers) as much as possible.

This period was marked by times of political unrest which disturbed ongoing work.

2.1.5. Period Four: Consolidation Phase (1990 - 1992).

Since the unbanning of the ANC and other organizations in February 1990, there has been a dramatic change in the nature of the relationship between SACLA and the State. Members of the State health structures are constantly wanting to visit the project, asking

about the work and asking members of SACLA to sit on local and national committees.

In 1991 SACLA was contracted by the W.C.R.S.C. (a governmental body) to train CHWs in one of the areas of Khayelitsha Site C. This is part of an experimental primary health care scheme where the government and non-governmental services are trying to work together.

SACLA has also been involved with non-governmental organizations in health policy discussions. In 1992 together with the Progressive Primary Health Care Network, SACLA set up a training centre for CHWs that will serve the Western Cape. The training centre will train CHWs for other communities and organizations, both government and non-government. As yet RWs will not be trained by the training centre, but a rehabilitation module for the CHWs will be designed by the SACLA rehabilitation team.

The SACLA staff and number of CHWs and RWs has grown considerably and now numbers over 100 people. CHW and RW co-ordinator posts were established and people experienced in community based work were promoted to these jobs. They provide support and back up for community based workers and do much of the administrative work. This enables the health professionals to do more of the work for which they are trained.

A management team has been established which is responsible for the management of the project. The Central Committee has been enlarged considerably and is more highly respected by the SACLA employees as a number of well-known people involved in community organizations are now members of this committee.

In this period, the work of SACLA has been subject to rigorous evaluation. Aspects of the CHW project have been evaluated, and the structures and functioning of the organization were evaluated by

outside consultants. This thesis is itself part of this process for the rehabilitation side of the project.

2.2. THE EVOLUTION OF THE SACLA REHABILITATION WORKER PROJECT.

2.2.1. The Vukani Centre and its Goals.

During the transition phase, in the second part of 1986, whilst trying to assess, analyze and plan a new way forward for SACLA, concern was expressed about the needs of the large number of disabled people and disabled children in the Site B squatter area of Khayelitsha. This concern was motivated by two reasons.

Firstly there are a large number of disabled children in the squatter camps near Cape Town, as their mothers bring them to Cape Town from the Transkei and Ciskei in search of medical assistance. Secondly there is no institutional care and very limited schooling available for Black disabled children (both physically and mentally disabled) in Cape Town.

Two members of SACLA, a nutrition worker and a physiotherapist, spent eight weeks going from door to door visiting people in Site B, asking them if they felt there was a need for a nutrition centre and a day care centre for disabled children. Everyone spoken to was very enthusiastic, and told them of children they knew who were handicapped in some way.

By negotiating with one of the headmen in the area, two plots of land were obtained on which two small prefabricated buildings were built, one to be a nutrition centre and the other a day care centre for disabled children. These two buildings were opened in January 1987.

The aims of the day care centre, which was soon named the Vukani ("stand up") day care centre, were:^{23,24}

1. To provide a support structure for the mothers of disabled children.
2. To provide a facility where mothers could leave their children when they went to work.
3. To make rehabilitation accessible and available to the disabled people in the area of Khayelitsha.
4. To facilitate an understanding of the condition, prognosis and treatment needs of the child, with the mother.
5. To demystify rehabilitation skills.

The day care centre was staffed by a physiotherapist and a convener. The convener saw to the running of the centre on a daily basis and gave routine treatment to the children. The physiotherapist assessed new children and together with the convener discussed treatment priorities, plans and methods.

Within a year over a 100 children had been seen. The different conditions seen included cerebral palsy, mental handicap, hydrocephalus, poliomyelitis and spina bifida. During 1987 and 1988 an average of 12 children a day were seen at the centre. The daily average in 1989 dropped to six children a day and in 1990 it dropped still further to four children a day. The Vukani day care centre was closed as a day care centre at the end of 1990.

The major reasons for the closure of the day care centre were:

- A. *Accessibility* - Khayelitsha is so large that Vukani was only accessible to a small section of the disabled community.
- B. *A change of focus in the RW project* - In keeping with the rest of SACLA, namely the CHW project, there was now a focus on home based care in the different areas, as opposed to centre based care.

C. A lack of resources - Vukani day care centre started as a tiny initiative to meet a need. However, as a small non-governmental organization, SACLA did not have the infrastructure, time, money or staff to develop a structured, well-functioning day care centre.²⁵

2.2.2. The Development of the Rehabilitation Worker Project.

Over four years then, the Vukani Day Care Centre became less significant, and more energy and resources were put into the development of the RW project, and the deployment of RWs in the community itself.

The first training course for RWs was attended by two CHWs. The area from which the CHWs came had a high CHW to people ratio, so it was felt that the CHWs were not overloaded and would have the time to work with disabled people.

This was not a success. The CHWs trained with rehabilitation skills, were very enthusiastic about their work with disabled people. However, they found that the more immediate work of being a CHW proved to be an obstruction to the more long term rehabilitation work. For example as they were setting out to visit a disabled child a person would arrive who needed a bandage. This would have to be done first so the disabled people did not see the CHWs for as much or as long as they needed to.

By the end of the first year, therefore, it was agreed that CHWs would not be RWs and rather that SACLA's RWs would all be mothers of disabled children who live in the areas in which they work. They were elected at a meeting of the community of disabled people (which according to the definition developed at SACLA includes disabled people and their families). It was felt that disabled people and their families are better equipped than others to work amongst the

community of disabled people, as they have had similar experiences themselves. The experiences and feelings of the RWs themselves as part of this community of disabled people are integrated into the practical training of the RWs.

2.3. PRINCIPLES GUIDING THE WORK OF THE SACLA REHABILITATION WORKER PROJECT.

2.3.1. Goals of the Rehabilitation Worker Project.

The initial goals of the RW project were:²⁶

1. To inform the family (mother in particular) about the condition of her child.
2. To teach exercises to the disabled person themselves and their family either to ensure that they reach their maximum potential or to prevent their condition from deteriorating.
3. To provide emotional support to the disabled person and the family. In the case of children this would usually be the mother who is the prime caregiver.
4. To ensure that rehabilitation is accessible, appropriate, affordable and acceptable to the disabled people who need it.*
5. To assist access to health and welfare institutions and resources.

To be accessible, people are seen in their homes. To be appropriate, toys or equipment for doing exercises are developed from what people have in their homes, rather than using unfamiliar and expensive toys and equipment. To be affordable, acceptable and appropriate people from the same community, who speak the same language and have the same belief system and who have had similar experiences work closely with the community of disabled people.

* This fourth goal is based on the WHO definition of primary health care as defined at the Alma Ata conference.²⁷

2.3.2. Home Based Rehabilitation.

SACLA has been mindful of the criticism that "Community Based Rehabilitation (CBR) is a second rate service for poor people"²⁸, so initially the rehabilitation project sought to relate to the high technology and Institution Based Rehabilitation (IBR) offered at the large hospitals in the greater Cape Town area, as these are the only places in which IBR is available for black people.

However, experience has led both the therapists and RWs at SACLA to question the value of IBR for the large numbers of disabled people living in squatter camps. The main reason is that the principles of IBR for physically and mentally disabled people were developed in developed countries,²⁹ and have since been imported into less developed countries. In this less-developed context IBR is inappropriate, inaccessible, incomprehensible (in a different language) as well as being of a poor quality. The service provided by IBR may help a few people (2-3%), but is irrelevant to the majority of disabled people.¹⁶ 80% of the disabled could be significantly helped by resources existing within the community.²⁹

Even centre based rehabilitation in the community is not accessible to many disabled people. This is due to two factors:

1. The squatter areas are large so that it is difficult for many disabled people to get from one area to another.
2. These areas are built on sand, through which wheelchairs cannot easily move.

In order to be accessible to disabled people, the RWs visit people in their homes. Each day the RWs are expected to do between six and eight home visits.

Home visits are the main features of the everyday activities of all CBR programmes....based on the philosophy that the family support structures are available to the child 24 hours a day for most of the child's developmental years.³⁰

The RWs see disabled people who have a severe problem or who will benefit from intense rehabilitation two to three times a week. The less severely affected child whose condition has plateaued is seen once a week or once every two weeks. The adult whose condition is stable is seen once a month. The RW will visit people who do not need to be seen regularly once every two to three months. If in the interim, the person develops a problem, he or she is encouraged to visit the RW at her house.

2.3.3. Holistic Treatment of Disabled People.

The RWs are expected to relate to disabled people as whole people and not as a specific physical or mental problem. This means that they need to relate to the disabled person as they would to any other person, to befriend his or her family, to listen and empathize with social problems and if necessary be involved in planning a solution.

When working with disabled children the RWs are encouraged to play with the child rather than to do a specific set of exercises. Talking and relating to the child is seen as more important for the child than a set exercise routine.

If the disabled person or (in the case of a child) the family do not want to be seen by the RW project, the RWs will explain the importance of what they are doing. If however, the person or family still insist, their right to decide what they want for themselves is respected and they will no longer be seen.

2.3.4. Involvement with the Family.

The RWs work closely with the family of disabled people, especially in the case of disabled children. Support for the prime caregiver is one of the major aims of the RW project. The RWs spend time educating the disabled person and his or her family about the cause and prognosis of the condition and ensuring that they themselves know how to treat and handle the person. This is of great importance as people are highly mobile and are constantly being lost by the RW project, either by returning to the Transkei or Ciskei or by moving to a new house, adjacent area or newly opened area.

2.4. REHABILITATION WORKER TRAINING.

2.4.1. Factors which Influence the Training.

A number of factors influenced the curriculum for training.²¹

A. *The work context.* In designing and planning the RW training course and in developing expectations of RWs at work, it is necessary to be constantly aware of the context in which the RWs work, and the many factors which affect this.

As noted in Chapter One, squatter communities in South Africa are volatile communities, leadership changes constantly, and the level of violence is very high. At times of political unrest, health and rehabilitation is not a priority for people. They are not interested in seeing a RW and are only worried about the safety of their family. Furthermore in the Western Cape these areas are extremely hot in summer and bitterly cold and wet in winter. Both in work and

training, sensitivity to what is going on in the community is essential so that the RWs can relate to people and their needs.

B. The strengths and limitations of the RWs. The RWs have limitations. Most of SACLA's RWs have had no more than four years schooling, had no idea how to use a diary when they started work, and speak very little English (the language the health professionals all speak). The training is therefore in the local language, Xhosa, and only essential notes are taken. Teaching is based on problem solving and is related to restoring and maintaining function in the person needing rehabilitation.

C. Principles of community based rehabilitation. A detailed discussion on the definition of CBR follows in Chapter Three (3.2.).

Through the way in which the training course is run and the manner in which work is done, it is hoped that the RWs and the community of disabled people will be empowered. The community of disabled people have a wealth of experience and understanding from looking after a disabled family member or from having a disability themselves. In the training this knowledge and experience is drawn upon, hoping to encourage people to develop confidence in what they already know. People are encouraged to contribute, question and disagree, so that both trainers and trainees are learning and teaching at the same time.

The training aims to equip RWs to be sensitive to all the problems a disabled person may have and to be prepared to be involved in these. The RWs must never see a disabled person as having only a physical problem which will be helped by exercises. In the training course the stigma attached to having a disabled child and the

problems a disabled person faces in trying to get a job are discussed. The value and need for people with similar problems to come together to discuss these problems and to work together to utilize available resources and to explore possible solutions is also discussed.

D. Traditional beliefs and cures. Many of the people with whom the RWs work understand illness and cure within the framework of traditional African beliefs. This has to be taken into account both at work and in the training course. The RWs are encouraged to listen to people sensitively, take them seriously and if people are determined to carry on with traditional cures (even if they are not working) to suggest they try Western medicine at the same time.³¹

E. The trainers. The initiator of the project, co-ordinator of the training course and author of this thesis is a rehabilitation professional. She still works weekly in different communities to ensure she does not lose touch with the disabled community at a community level. In the long term it is hoped that the training will be done by the rehabilitation co-ordinator, who was once a RW herself.

A number of other people are drawn in to assist with the training course: the disabled community, primary health care trainers, community development workers and people who have experience in working with different handicaps such as mental handicap and visual impairment. In 1992 *Disabled People South Africa* (DPSA)³² a national organization of disabled people and mothers of disabled children, have employed a fieldworker in the Western Cape. It is hoped that he will be drawn into the course.

2.4.2. Training Course Content.

The training has been divided into two sections - an initial training course of four weeks, and an ongoing training programme. During the initial training course the RWs are exposed to the broad scope and variety of the work. In the ongoing training, particular conditions or issues are dealt with in more depth when the RWs come into contact with these in their daily work.

The content of the initial training course has six main themes.²¹

A. The community.

The work is community based, so the training course is run in the community. A number of afternoon sessions are held where the RWs are expected to do home visits and visit schools and churches in their area, so that they get to know their community.

Together, the RWs and a facilitator discuss what is meant by "the community". A brief community analysis is done defining the different groupings that are present in the community, the resources, power structures and people within the community who are respected and powerful. The RWs need to know and understand the community they are working with to understand how it works and makes decisions.

The focus is then narrowed down to the disabled community. Their common needs and problems, how to get to know where disabled people live and which resources could be used to address these problems are discussed. Community development is part of the work of the RWs and they need to know what resources are available in the community and how to draw on these as together with mothers they establish support groups for mothers of disabled children, or together with disabled people they set up employment projects for disabled people.

In trying to develop attitudes of caring, compassion, gentleness and confidence, role plays are done which focus on listening to each other, how to share bad news, how to respond if a person cries and how to do home visits. Each person gets a chance to practise these skills which are needed during their work.

B. Primary health care.

A section on primary health care is included as C.B.R. is considered to be part of primary health care. This is to encourage the RWs to have a holistic view of health and not to see disability in isolation from the rest of life. Disability can be used as a springboard to discuss broader health issues. For example, a child with poliomyelitis can be used to initiate a discussion with mothers of disabled children about why immunizations are so important, or a child who cannot walk as she is malnourished could be used to initiate a discussion on nutrition and what a child needs to develop both physically and emotionally.

In addition, disabled children are often ill, so if the RW has basic knowledge about common illnesses, this builds up her credibility. The RWs do not treat these illnesses, but know when, where and how to refer people for treatment.

C. Conditions and treatment.

The most common conditions of disability seen in adults and children are covered. Every year the patient data from the previous year is analyzed and the training course adjusted if necessary, to ensure the training is appropriate for the work that has to be done. A substantial part of the course focuses on children who have moving

difficulties and are either spastic (tight and stiff) or hypotonic (floppy) or have delayed development, as these comprise the largest group of disabled people (38%).¹⁸

The RWs are expected to know what caused the disability, what is likely to be the outcome in a years time, and in five years time, and what can be done to assist the person in attaining their fullest potential, so that they can explain this to the family.

D. Problems which may occur.

In this section the problems experienced by those who have severe disabilities, such as contractures and pressure sores, are discussed together with prevention and management.

There is discussion about the feelings that the community of disabled people experience and the value of support. It is noted how the job of the RW is often not to do any specific exercise but just to listen to the feelings of the person and their family, and if appropriate to share her own feelings.

E. Normal body functions.

This section is done together with the section on conditions and treatment, so that the functions of the body are learnt together with problems which can occur if there is a dysfunction of the body. For example a discussion about the way in which the brain functions takes place during the session on cerebral palsy.

F. Special needs of children.

Both physical and emotional needs are mentioned as necessary for children to develop into confident happy people. The value of stimulation and play is emphasized and a workshop is held in which toys are made out of materials which can usually be found around and about the community.

2.4.3. Ongoing Training.

After the RWs have finished their training course they start working in their community doing home visits. Once a week a rehabilitation professional or the rehabilitation co-ordinator spends time with each RW, seeing disabled people. They discuss problems the RW is having with her work, and discuss each disabled person, deciding with the disabled person on the necessary treatment and action that needs to be taken to assist that person.

Common problems are picked up either by the professionals, co-ordinator or the RWs and then workshops are organized to deal with these problems. Workshops are held once a month. Linking ongoing training with work in this way ensures that the training is relevant to the needs of the RWs in their work. Whenever applicable, the knowledge and experience of professionals in the urban centre is drawn on and they are involved in the running of workshops.

Ongoing training is a crucial part of the work as the RWs find it both encouraging and stimulating. It also provides a time for the RWs to be supported and encouraged as they can so easily become depressed and disillusioned about their work.

2.5. SUPPORT SYSTEMS FOR THE REHABILITATION WORKERS

Support for the RWs is considered to be very important for a number of reasons.

Firstly, disabled people not only have physical and mental problems but often more demanding emotional, financial and social problems.

Secondly, even highly skilled people with knowledge and access to the resources available can become depressed and feel they are achieving nothing. A tremendous amount is expected of these grassroots community workers. The RWs have limited skills and limited access to resources. Feelings of despair and depression will affect the RWs in their work.

Thirdly, the initial training course is short and ongoing training is needed to ensure that all areas are covered. Finally, by its nature community work is demanding. The RWs may not see another RW for two weeks and feel isolated.

Support for the RWs is thus provided in a number of ways.

2.5.1. SACLA Support

Many of the RWs live in different areas quite a distance away from each other. In all the areas where there are RWs there are CHWs. The RWs are introduced to the CHWs, encouraged to refer people from one to the other and to work together whenever possible.

Once every three months everyone who works for SACLA is expected to attend a General Staff Meeting. At this meeting people are encouraged to get to know each other, information about

administrative issues is discussed and work aims and objectives are planned and evaluated.

2.5.2. Other Organizations.

Time is spent developing links with other organizations who work in the same geographical area and in the field of disability. Workshops have been organized for the RWs of the different organizations in the Western Cape so that together they can learn and share common experiences. The RWs have been encouraged to become involved in DPSA.

2.5.3. Rehabilitation Therapists.

Once every two weeks a rehabilitation therapist (either a physiotherapist or occupational therapist) spends a morning with each RW.

The primary function of the rehabilitation therapists at SACLA is the passing on of rehabilitation skills to the RWs. During the time the therapist spends with each RW, disabled people who are new to the RW are assessed. The major problems are discussed together with the RW, the disabled person and the family and the aims of treatment and the methods which should be used to achieve these are decided on.

The therapist will take time to ensure the RW knows exactly how to perform the activity or technique and how it should be progressed. During this time the therapist will also be aware of further training which may need to be dealt with in a workshop.

The secondary function of the therapist is to take responsibility for a number of tasks which are beyond the scope of the RW's skills. These include:

1. Links with medical services to make doctors appointments, obtain medical records and facilitate acquiring medication.
2. Links with social welfare services with regard to making appointments with social workers, sorting out grants, unemployment or schooling.
3. Ensuring equipment is acquired or repaired.

The tertiary function of the therapists is to initiate groups or projects to meet a particular need in an area and to facilitate their starting. However, it is not the responsibility of the therapists to maintain these groups.

2.5.4. The Rehabilitation Co-ordinator.

The RW project has had a rehabilitation co-ordinator for two years. The co-ordinator was a RW herself. Her prime responsibility is to co-ordinate the RWs.

She regularly spends time with each RW, seeing disabled people but more importantly discussing how the RW feels about her work and listening to any problems. The co-ordinator also helps with people the RW is finding difficult because of family, social, emotional or housing problems. The co-ordinator checks each RW's statistics, which are then discussed at the RW's meeting. She helps sort out conflicts between the RWs.

The co-ordinator is taking on more and more of the initiating and maintenance of groups or projects in an area. She also chairs the RW's meetings, will attend community meetings with the RWs and acts as a link person with DPSA as well as township organizations.

2.5.5. Doctor's Clinics.

Twice a month a doctor from Red Cross Hospital's Development and Assessment Clinic comes to Site B, to run a clinic to which children seen by the RWs come. This has been necessary as so few mothers are able to keep appointments at the hospitals due to financial problems. However, last year these clinics were held irregularly and for months not at all.

2.5.6. Toy Libraries

These are run by a small organization in Site B and Site C. They have proved to be a great asset to the RW project. They have been a support to the RWs and have given them credibility in the eyes of the mothers of the disabled children with whom they work.

2.6. OTHER IMPORTANT CONCERNS IN THE REHABILITATION WORKER PROJECT.

In this section a further four important concerns are discussed. The first two namely funding and the relationship to the CHW project are ongoing concerns that have been experienced since the beginning of the RW project. The other two, support groups and employment projects, are issues broader than basic medical and rehabilitation needs but have emerged as important concerns of the community of disabled people.

2.6.1. Funding

Whether CHWs and RWs ought to be volunteers, supported in kind by the community or paid through government or other funds, has been much debated.³³ SACLA is of the opinion that RWs will always have to be

paid through government or other funds. The disabled community with which SACL A works is oppressed for a number of reasons. They are Black, the prime caregivers are usually women and they are disabled. They are thus often poverty stricken and destitute and could never afford to pay for basic rehabilitation services.

SACL A does not feel that the CBR provided by the RWs is a second rate service. It is felt that CBR provides as good a service as IBR does and at far less cost. It does cost, however, and this cost will never be borne by the disabled people who live in the squatter camps.

Searching for funding is an ongoing anxiety. SACL A believes that the State should fund primary health care work, including rehabilitation. To ensure flexibility so that primary health care and CBR can respond to individual communities needs, the money should be given to non-governmental agencies to administer, with minimal state control.

State services have publicly announced their commitment and willingness to fund CBR, but this has not materialized. The W.C.R.S.C., which is responsible for preventative health care in the Western Cape has funded 20 SACL A CHWs in Site C, but has not been prepared to fund RWs.

Funding for the SACL A RW project is at present provided by an American Foundation, the Henry Kaiser Foundation and a subsidiary of an American pharmaceutical company Warner Lambert.

2.6.2. Relationship to the Community Health Worker Project.

The RW project is much smaller than the CHW project. There are eight times as many CHWs as RWs. Because of the difficulties of having a disabled child, the RWs have had to stay at home much more and have

had an extra burden to bear. They tend to be quieter and less educated than the CHWs. In addition some of the CHWs are involved in political activity through which they become more articulate. As a result of this the RWs often feel undermined and threatened by the CHWs.

2.6.3. Support Groups.

Mothers of disabled children often expressed the need for a place to leave their children during the day. Most mothers wanted a big centre with trained staff and transport. The SACLA RW project did not feel able to respond to this request, but suggested support groups. These would be small local groups organized and run by the mothers themselves. Together the mothers in an area would decide who could run the support group, where it would be and whether and how much this person would be paid.

There are at present four support groups operating in different areas. Although they were initiated by the SACLA RWs, they are now all affiliated to DPSA. DPSA provides ongoing support and training for the conveners who run the support groups on a day to day basis and links with other similar groups.

SACLA provides some ongoing support by running toy workshops with the convener and mothers so that there are toys available in each support group, by sending the RWs to the support groups twice or three times a week to help the convener treat the children, and by providing food and equipment.

2.6.4. Employment Projects.

SACLA has been involved in helping two small groups set up handcraft businesses in their own homes. These groups now function independently of SACLA and have established close links with DPSA.

The one group which calls itself Masincedane, together with DPSA and SACLA called a meeting of all the disabled people in Khayelitsha. The aim of this meeting was to introduce DPSA to the disabled people of Khayelitsha and to get people together to start discussing their needs. The meeting was a great success and a number of subsequent meetings have been held.

2.7. CONCLUSION.

In this chapter the history of the SACLA Health Project and the rehabilitation project has been discussed, and the issues leading to the development of the current use of RWs working in a community have been identified. The principles guiding the work of the RWs were analyzed and the importance of the basic concerns of accessibility, appropriateness, affordability and acceptability was emphasized in the light of the socio-economic context of the project described in the previous chapter.

This chapter also analyzed the training given to the RWs, including the factors which influence it, the content of the initial course, and the ongoing training and support from the project. An adequate background to the socio-economic context and the principles and structure of the SACLA RW project has now been developed against which the evaluation of other similar projects can be discussed (Chapter Three) and the focus of the present evaluation can be understood (Chapter Four).

CHAPTER THREE: LITERATURE REVIEW

In this chapter, through a survey of literature concerning the evaluation of some community based rehabilitation (CBR) projects worldwide, the key concerns of these evaluations will be identified and the present evaluation located in this context.

3.1. DISABILITY PREVALENCE

In 1976 the WHO estimated that 10% of the world's population was disabled.³⁴ More recently these figures have been disputed. Prevalence rates for moderate and severe disability have been estimated at 7.7% in more developed regions and 4.5% in less developed regions, with a global average of 5.21%.¹⁷

Disability prevalence is higher in more developed countries for two reasons:

- Age composition of the population group: The older the population the higher the incidence of disability.
- Environmental influences: A high level of urbanization with more traffic, industrial development, the use of hazardous chemical substances and machinery, deterioration of air, water and sanitation systems all increase the incidence of disability.

Disability prevalence in less developed countries will increase as the age composition of the population group increases and there is increased exposure to the environmental influences listed above. It is estimated that in 35 years the disability prevalence in less developed countries will increase to 6%.¹⁷

3.2. COMMUNITY BASED REHABILITATION

CBR was introduced by the WHO in 1976. It was seen as an approach for providing services and training for disabled people, particularly in developing countries. CBR was seen as an integral part of primary health care and part of the WHO strategy for "Health for all by the Year 2000."

CBR is a strategy for improving service delivery, providing more equitable opportunities and promoting and protecting the rights of disabled people. It requires integration between the health, welfare, educational, vocational and legislative sectors. It aims at full representation and empowerment of disabled people.¹⁷

CBR is a range of methods that help support disabled children in their families and communities. It is not represented by one set of techniques or easy solutions. It may involve working through rural health assistants or primary school teachers. It may involve the counselling of parents by social workers or, preferably, a combination of these. It should link with existing specialist services. It must be sensitive to the expressed needs of parents of disabled children and of course of disabled people themselves.³⁰

This definition of CBR above is useful and emphasizes the need for CBR to be sensitive to the needs of disabled people and their families. However, there is an emphasis on the use of professionals and rural health assistants to the exclusion of disabled people and resources in the community. While the WHO definition below is not a complete definition, it stresses the importance of including disabled people and resources available within the community.

Community based rehabilitation involves measures taken at the community level to use and build on the resources of the community including the impaired, disabled and handicapped persons themselves and their community as a whole.¹⁶

The working definition of CBR in the SACLA RW project draws together these concerns mentioned above as one of the strongest assets of the SACLA RW project is the use of families of disabled people in providing a rehabilitation service:

CBR is a range of methods that help support disabled children in their families and communities. It is not represented by one set of techniques or easy solutions. It should link with existing specialist services. It must also build on the resources of the community, and release the potential of disabled people and their families, while being sensitive to their expressed needs.²⁵

Different models of CBR have developed in attempts to apply these principles. Momm and Konig³⁵ have suggested that the different CBR projects can be divided into two different models of CBR. Although this differentiation is useful it is based on one aspect of CBR only, the relationship of CBR to other existing rehabilitation services:

CBR exists basically in two forms: to one school of thought CBR is the effort to entrust members of the family and community with the task to perform rehabilitation functions. Based on the model of the grassroots primary health care programme, rehabilitation was simplified to the extreme to allow even the illiterate community member to carry out therapeutic exercises and to produce and use simple aids and devices.

The other school of thought conceived CBR as an outreach or extension service based on the objective to bring professional rehabilitation services to a large number of disabled people, in particular in the rural areas, and to refer people in need of more sophisticated services such as are available in rehabilitation centres.

In the first case a CBR project is entirely non-institutional, in the second case it is a complementary programme which needs institutions as referral stations and technical support bases.

As was described in some detail in Chapter Two, the SACLA RW project was developed with the second definition of CBR outlined above in mind. Based in a peri-urban area a lot of time and effort has been

spent linking with other services so that each disabled person or child has access to the best services available.

In South Africa where rehabilitation services have traditionally only been available for the rich and privileged minority, it is of crucial importance that each disabled person has the best service available to them, as otherwise CBR will be seen as a second rate service for poor people.

3.3. EVALUATION.

The WHO has defined evaluation as:

... a systematic way of learning from experience and using the lessons learned to improve current activities and promote better planning by careful selection of alternatives for future action. This involves an analysis of different phases of a programme, its relevance, its formulation, its efficiency and effectiveness and its acceptance by all parties involved.³⁶

The UNDP¹⁷ has set guidelines for project evaluation:

Relevance: Does the project meet the needs of the people? Does its purpose remain valid and pertinent?

Effectiveness: Did the project achieve its objectives?

Efficiency: Were the resources provided used in the most efficient way? What outputs were produced and how well?

Sustainability: Can the project stand on its own legs after the assistance has been withdrawn?

Impact: What effects has the project had on its surroundings (institutional, technical, economic and social)?

Helander has reflected on these five guidelines as they pertain to the evaluation of CBR projects.¹⁷ He goes on to argue that CBR projects will always be relevant as there will always be disabled

people in society. To measure *effectiveness* it is important to be realistic and take into account constraints and resources. A number of different outputs can be used to evaluate *efficiency* eg. are the staff competent, does their training equip them with the necessary skills, how are personnel managed, how many disabled people and their families participate in the project? *Sustainability* can be measured by assessing government support for the project and whether the project could survive without external funding. *Impact* could be measured by assessing whether the communities attitudes and behaviour to disabled people have changed and whether disabled people are coping better.

The present evaluation is motivated by similar concerns as those expressed in the WHO definition. It seeks to improve the services offered by the RW project by a systematic evaluation of current activities. The key themes in terms of the UNDP guidelines that are important in this evaluation of the SACLA RW project are (i) its *effectiveness* in terms of the stated objectives of the RW project; (ii) its *efficiency* in terms of staff competency and training, and the passing on of skills to caregivers; and (iii) its *impact* on the lives of disabled children and their families.

A number of other similar projects have been evaluated and the following section examines some of these.

3.4. EVALUATION OF COMMUNITY BASED REHABILITATION PROJECTS

The activities carried out by CBR projects vary. Different activities have been evaluated by a number of CBR projects. It is crucial that the core activity of the project is evaluated.³⁷

Different aspects of a CBR project may need to be evaluated in stages. In the SACLA RW project home visits are considered to be the core activity of the programme. As noted earlier:

Home visits are the main features of the everyday activities of all CBR programmes....based on the philosophy that the family support structures are available to the child 24 hours a day for most of the child's developmental years.³⁰

For this reason home visits were evaluated by asking the mother or caregiver her feelings about her child and the RWs and measuring a number of outcome indicators.

3.4.1. An Outline for Classifying Different CBR Evaluations.

Helander has suggested that there are three different aspects of CBR projects which need to be evaluated.¹⁷

A. An Evaluation of the Technology.

The progress of disabled people following the implementation of a CBR project is measured. A careful baseline study is needed followed by an equally careful evaluation of the achievements a set time after the training of local people has been implemented.

B. An Evaluation of the Service Delivery System.

Service delivery may take many forms. An example of one system would be the training done at home by the family member, supervised by a community worker who has the support of a trainer/supervisor and a referral system. For a complete review of the delivery system a number of sectors will need to be covered: training of the workers, performance of the families, support of the workers, links and

referrals to the health and welfare sectors, links with special education and vocational institutions.

C. An Evaluation of the Management System.

Crucial issues to be evaluated here would be:

- the extent of community participation
- sustainability and self-reliance of the project
- commitment of the government and resources provided by it.

In the literature there is documentation of a number of different evaluations. In the next section some of these evaluations will be discussed under the different aspects of the project evaluated as outlined above. Because the evaluation of the SACLA RW project is an evaluation of a service delivery system, four similar evaluations will be examined in more detail below. Finally two studies which have qualitative data on CBR evaluations will be considered.

3.4.2. An Evaluation of the Technology with some Examples.

It is very difficult to show that rehabilitation techniques and activities used in the treatment of children with moderate or severe cerebral palsy facilitate normal movement and development.

Improvements in the child's condition may be due to a number of other causes including the normal development of the child. The Bobath centre in London which is famous for its development of a technique used to treat both children and adults who have neurological damage, is hesitant to claim quantifiable success.³⁸ Due to the difficulty in measuring quantifiable success, particularly in children, not many

studies have been done to evaluate technology in developed countries where intensive one on one treatment is done by highly skilled professionals.

A. Guyana.

O'Toole,³⁹ working in the rural areas of Guyana, did a technological evaluation of the programme. All the children were assessed before the programme began and then a year later after they had been treated by community people trained to work with disabled people. To assess the children the Griffiths developmental test was used together with assessments by independent evaluators and the mothers.

A significant improvement was demonstrated. The degree of progress did not seem to depend on the educational or financial level of the parents or the severity of the impairment. Most significant was the involvement of the parents. 17 out of the 20 mothers found the project helpful and attributed positive changes within their children to the programme. Initially 18 of the mothers expressed sadness, depression and anxiety about their children. By the end of the year 11 of them had more positive feelings.

This is one of the few evaluations of a CBR programme in which an attempt is made to evaluate service delivery and to validate the results scientifically. Although the sample size was small, the number of people involved in the programme was small. The sample was a representative sample of the types of disabilities seen in the programme.

In conclusion he deduced that simplified rehabilitation is acceptable and that training people from the community to work with disabled children is feasible.

B. Vietnam.

Mendis,⁴⁰ in an extensive evaluation of a CBR programme in Vietnam did a technological evaluation as part of a much broader evaluation. Family members of disabled people were trained to perform treatment activities.

Four areas of rehabilitation were used for measurement: Self care activities, mobility, communication and socialization. The achievement ratios for these activities in the Vietnam were as follows:

| | |
|---|-----|
| - independence in self care | 85% |
| - independence in mobility | 90% |
| - communication | 40% |
| - socialization within family and community | 81% |

This was an unpublished report. The scientific basis of the evaluation is unclear as the summary contained no detailed methodology or data with which the results could be validated. It was noted that the high success levels recorded in the areas of greatest need indicate a high level of effectiveness.

C. India.

Menon,⁴¹ in an evaluation of a CBR programme in Southern India, noted that members of the family of the disabled and health workers were prepared to be involved with disabled people on an individual level and that teachers and community leaders could be persuaded to tackle issues confronting disabled people in society and at a community level.

55% of the cases studied showed improvement in their overall functioning. The sample size was large which validates the results.

However improvement was not based on objective or scientific measurement but on the opinion of the family only which does not validate the results.

3.4.3. Evaluation of the Management System with some Examples.

A. Sudan.

Baker,⁴² in South Sudan, initiated a CBR project which involved the local community and government departments. Local people were trained to work with disabled people. This project has continued to function in spite of the escalation of civil war and virtual siege of the city where this project is based. The sustainability of the project under adverse circumstances and the commitment of the government to it are positive indicators of the project.

This was a descriptive study and the data was not validated in anyway. The article was written soon after the author returned from the Sudan. The long term viability of projects initiated by expatriates has been questioned.¹⁷ Although reasons were given as to why the project should sustain itself, no indication is given as to whether this did happen.

B. Nepal.

Helander¹⁷ analyzed the evaluation of Arnold which assessed the management system of a CBR programme in Nepal. Children attending family support programmes were observed and it was deduced that these are an effective way of giving the child a chance to develop his potential and find a useful place in the community. He argues that

CBR programmes are a creative redirection of resources to develop and expand rehabilitation services. Much can be done to prevent disabilities and assist those who are disabled, but the will to deliver is essential. Political goodwill is required and governments have to be committed to make rehabilitation therapists available for the support of community RWs. Without the support of RWs by therapists a programme is doomed to failure. The scientific basis of this unpublished report was unclear as the summary contained no detailed methodology and data validating the research.

C. Vietnam.

Mendis⁴⁰ also did an evaluation of the management system of the programme in Vietnam.

Community participation.

After the programme had been implemented for a year community leaders and neighbours were interviewed. They showed a positive change in their attitude to disabled people which they attributed to an increased understanding of disability and the success they had seen in the lives of individuals being rehabilitated. The positive impact of the project on individuals being rehabilitated increased the confidence of the community in the leaders and led to increased community spirit, motivation and involvement in other community activities. There had been increased community participation in the project which had strengthened relationships both within and between families. Initially the political leadership had been concerned by the focus on rehabilitation but after the first year saw the project as a social development project.

Financial self-reliance.

For a period of four years modest financial contributions from the Swedish *Save the Children Fund* were used to pay for consultants, training courses and pedagogic materials. Contributions from the community paid for all costs of the training course (midday meal, tea, stationary). Petrol, printing and transport were financed by the District Health Office.

This project was financially self-reliant and had the financial support of the local and provincial government. Financial self-reliance and government support are positive indications of the management system of the project.

3.4.4. Evaluation of Service Delivery and In-Depth Discussion of Some Examples.

The first evaluation described below is different to the other programmes as it is based in a developed area: London. The other four evaluations are done in more detail as they are in less developed regions, more similar to that in which the SACLA RW project operates.

3.4.4.1. London: Informal Carers in the Community.

This evaluation has been included here as the issues it raises are similar to those raised by CBR programmes in less developed areas even though it was done in London, United Kingdom. Robinson⁴³ worked with informal carers of chronically ill and disabled people. These family members had received no formal training in caring for their disabled relative.

She noted that the service provided and care given by informal carers is adversely affected if the carers are not supported.

Informal carers who in London are often elderly women, suffer from emotional stress and physical exhaustion, are often socially isolated with financial difficulties, have minimal assistance and no relief.

She concluded that for service delivery to be effective these carers have to be emotionally supported, provided with an understanding of disability, taught handling skills and linked with existing community services. They also need to be recognized and have time to associate with people outside the house.

This article was descriptive highlighting the plight of informal carers and the implementation of a strategy to support them. No formal data was used to validate statements made and there was no description of the methodology used to collect the information. There had been no formal evaluation of the educational programme for informal carers.

The following four evaluations of service delivery systems discussed all form part of a broader evaluation of each project. Other aspects of the service delivery system of each project were evaluated as well as the management systems. As the present evaluation focuses only on home visits, only the home visiting programme in each case will be discussed.

Not all programmes refer to the people from the community trained to work with disabled people as RWs, however for simplicity these workers will all be referred to as RWs. The information collected during these evaluations was all qualitative, whereas the present evaluation concerned both quantitative and qualitative data.

3.4.4.2. The MENCAFEP CBR Programme based in Sri Lanka.

This was an evaluation undertaken by Gunawardena et al.⁴⁴ One of the prime aims of this programme is to work with parents, helping them understand the problems of their disabled children and giving them guidance on how to help these children. By working with the family in this way it was hoped to facilitate the integration of these children into the community.

The parents were very appreciative of the home visits and found the contact useful. No parents suggested an alternative method or content to the visits. On the whole the parents recognized that the staff visited as often as possible. One or two parents thought that more visits should be made. A number of parents of older children were concerned that there would be no support for them or their child after the child was 16.

The issue of most concern to the evaluators was that the teaching during home visits was never directed through the parents. To deal with this a number of recommendations were made:

- The activities should have been designed to encourage the family to apply particular ideas or teaching methods with regard to communication skills or self help activities such as work in the house or garden.
- The staff needed to establish specific learning objectives for each child, based on the child's home needs and linked to the school's teaching programme.

In this report there was no detailed methodology or results with which the findings could be validated. No indication was given of the number of people involved in the project, how they were selected, the size of the study sample or who conducted the interviews.

3.4.4.3. Evaluation of the Kwibezi CBR programme.

This was an evaluation undertaken by Saunders and Zinkin.⁴⁵ This programme operates in the rural areas of Kenya. It is part of a broader health scheme which includes a health centre, traditional birth attendants and community health workers, nutrition, well-sinking and protection of water points. There are strong links between the CBR programme and the other primary health care programmes.

The objectives of the CBR programme were to identify and develop simple rehabilitation plans for children under the age of 15 regardless of the type of disability. Home visits were considered to be an important part of the programme as the home visit was often the first point of contact a disabled person and their family has with the CBR programme.

For the evaluation twenty families were visited and the following questions asked:

- How long had the family been involved in the programme?
- Home visits: Who visits them?
How often does she visit?
Is the frequency of visits sufficient?
What is the content of a home visit?
Is the family satisfied with the visits?
- Equipment: What is used?
Who made it?
- The parent's view of the future of their child.

A. The Families' Feelings about the Home Visiting Programme.

Two families complained that they were not visited regularly, but all the other families valued the visits immensely and thought that the service offered was excellent. Families looked forward to the

visits. The RW is often the only community worker that the family sees, so their advice is sought on many issues.

Visits to families with severely disabled children had provided the incentive for parents to work in a positive and structured way with their child. Without these visits these children would have been ignored in the family who lacked the knowledge that something could be done and that it was within their own means and ability.

The families' feelings about the visits were predominantly positive. The home visiting programme promoted attitude changes in the parents, family and community at large. It had also provided much needed emotional support to families with severely disabled children.

B. The Content of the Home Visits.

The content of the home visits was not as positively reviewed. The parents used a limited range of passive movements and massage for physically disabled children. These were not always appropriate. Insufficient emphasis was given to the relevance of activities of daily living and to variety in play activities.

It was recommended that the RWs have more training in behaviour modification techniques and task analysis. They would then be able to teach parents to teach their mentally handicapped children by breaking tasks into smaller attainable steps.

By spending time with severely disabled children with multiple handicaps the RWs had increased the credibility of the Kwibezi project in the eyes of the community and improved the mental health of the parents.

C. Conclusion.

20 families were involved in the sample. This is a relatively large sample compared to the number of families involved in the project. These families were randomly selected. Two aspects of the methodology used lead to questions about the validity of the results. Firstly, the objectivity of the results is questionable as staff members were involved in a participatory evaluation of the home visiting programme. Secondly, five teams were involved in interviewing four families each which leads to questions about the consistency of the results.

This evaluation showed that there are effective community solutions to a significant number of problems. Many children provided with medical rehabilitation were able to attend school and become fully socially integrated. Parents became involved in the home-based programme, local teachers are encouraging integration in the schools and community awareness of disability is increasing. This increased community awareness lessens barriers faced by disabled people in the community.

3.4.4.4. An Evaluation of the CBR Programme in Zanzibar.

This was an evaluation undertaken by Juma and Miles.³⁰ The aims of this project were:

1. To provide services to individual disabled children in their homes and to encourage self-reliance.
2. To raise awareness of disability amongst parents, in the community and in the relevant government ministries.
3. To demonstrate that rehabilitation can be effectively provided in the community and therefore could be replicated in other parts of the islands.

In this evaluation the relationship of the RW to the family and the child was examined in detail. In the current evaluation the focus of the evaluation was on the caregivers relationship to her disabled child.

12 families were visited out of the 56 families involved in the project. This sample size although small was not small in relation to the rest of the project. The children involved formed a representative sample of the types of disabilities seen in the programme and came from the different geographical areas in which the project operated. It is not clear from the report who interviewed the families. Only qualitative data was collected.

Questionnaires were drawn up which focussed on the relationship between the RW and child, the RW and caregiver and the content and style of the RWs activities in the home. The parents were asked about their understanding of the projects objectives and what they had gained from the project so far. The RWs were asked about their general role in the project and specific objectives for the sample of families visited.

A. Relationships between the RW and family.

It was observed that the RWs have been fully accepted by the families and have developed some trusting relationships. The disabled child in each family was excited to see the RW when she arrived.

B. Activities carried out during visit.

The RWs concentrated on physical activities to encourage mobility and activities of daily living. There was an absence of toys (a few home made toys were found in homes), pictures for pre-school work, language development and general stimulation.

Mobility aids supplied to the children were all being used correctly. The RWs started working with the child immediately. They did not spend time making the child feel at ease and did not find out how the child had progressed since the last visit.

The RWs worked directly with the children and excluded the caregiver, who was often eager to be involved.

In conclusion it was noted that the RWs have the confidence and skills to work with children who have physical disabilities, but need more training to enable them to work better with children who have other problems such as mental handicapped and hearing impairment.

3.4.4.5. Evaluation of the Nairobi Family Support Services.

To evaluate the home visiting programme, 42 families were visited.²⁹ A questionnaire was used to evaluate the home visiting programme. It had two parts: In the first part the evaluator observed how the RW carried out activities with the disabled child. In the second part the parents were asked about their understanding of their child's problem, their attitude to their child and the services provided by the Nairobi Family Support Service (NFSS).

A. Relationship between the RWs and the Parents and Children.

RWs were well accepted by the parents, family members and neighbours. They were all known by name and had established a trusting relationship. All the children visited were excited to see the RW, who made an effort to establish a rapport with each child in turn. In some cases the RW was unable to sustain the child's interest whilst she tried to perform activities with the child. Parent and family involvement during home training was non-existent.

B. Planning of Home Visits.

The parents were not involved in setting long and short term goals for their child or in planning activities to achieve these goals. The activities the RWs performed with the child did not progress in a meaningful way. The RWs themselves had no clear idea of which skills needed to be achieved for each child and each child was given the same activities to perform regardless of their special needs. The RWs did not evaluate the progress made since the last visit, adjust activities accordingly and did not teach the parents how to do new activities.

Recommendations.

Good baseline data is needed for each child. Ideally each child needs an in depth medical, social, psychological and educational assessment. From this the child's deficits and potential abilities can be determined and the child's abilities and strengths built on in planning medical, social and educational interventions. The RWs need to plan with the parents specific long and short term objectives with

each child and the activities needed to achieve these objectives. These need to be recorded.

More than half of the children involved in the programme were visited which validates the results. They were randomly selected. The data which was collected was extensive but only qualitative data is contained in the report. Staff members were involved in a participatory evaluation so that the validity of the results is questionable for two reasons. Firstly, it is difficult for staff to be objective about their work. Secondly, for those being interviewed, it is inhibiting to respond to the workers of the project for fear of being ostracized at a later stage.

3.4.5.5. Summary of the Recommendations of the Four Home Visiting Programmes Described Above.

Families must be included in setting long and short term objectives and planning activities to reach these objectives. The families must be included in activities during home visits.

Good baseline data is needed for each child. Up to date record systems need to be maintained. These should include baseline data, activities planned to achieve these objectives and the date when these activities are mastered.

Children with different needs need to be given different activities. The RWs need more skills in working with mentally handicapped children or children with communication problems.

Before starting to do activities the RWs need to spend time making the child feel at ease and find out how the child has progressed since the last visit.

3.4.5. Qualitative Research.

3.4.5.1. Botswana.

Botswana was one of the countries in which the WHO manual for training the disabled in the community was tested.⁴⁶ The success of training local supervisors to do rehabilitation in the community was then assessed. To assess the project a workshop was held at a central venue and each local supervisor presented two cases for discussion. Each local supervisor selected the two cases to be presented.

Although the results are interesting and presented in a quantitative form, their validity is questionable for two reasons. Firstly, the objectivity of the local supervisors with regard to their work is questionable and the results were not confirmed in any way. Secondly, the sample was not randomly selected and was very small.

3.4.5.2. Zimbabwe and the Philippines.

Lagerquist¹⁷ in 1991 did a scientific evaluation comparing the CBR programmes of the Philippines and Zimbabwe. Using a sample matched for age, sex, living area and type of disability, he compared 106 people in the Philippines to 100 people in Zimbabwe. For both countries after the implementation of the CBR programme there was a considerable reduction in the severity of the disability, social integration was improved, many more disabled children were attending school and many disabled adults were employed at least part time.

The validity of the results was confirmed by the methodology and data collected. The sample sizes were large and matched. The criteria for measurement were standardized and the results subjected to epidemiological investigation.

3.5. CONCLUSION.

Having discussed the prevalence of disability in less developed regions and defined CBR this chapter has examined the purpose of evaluating CBR projects, identified three types of evaluation and illustrated these through means of a literature survey. Because the present evaluation is classified as an evaluation of the service delivery system, five similar evaluations were examined in detail.

In all five of these evaluations, home visiting programmes were shown to be the core activity and the basis of all other aspects of the work. The involvement of the family in caring for the disabled person was also identified as a key area of importance. These two concerns - home visiting programmes and the involvement of the family - are also central to the SACL A project and therefore form the focus of the present evaluation, which now follows.

CHAPTER FOUR: METHODS.

4.1. DEFINITION OF TERMS USED IN THE EVALUATION.

The background to the SACLA RW project and broader issues to do with CBR have been discussed in the previous three chapters. This establishes the background for the evaluation of the RW project which is the central concern of this thesis, and the methods (Chapter Four), results (Chapter Five) and discussion (Chapter Six) of this evaluation now follow. The definition of technical terms relating to the evaluation and used in these chapters now follows in alphabetical order.

Added exercises - This refers to the exercises that were performed by the caregivers, which were not taught by the SACLA therapists. These exercises were scored in a similar way to the taught exercises.

Average Performance Score (A.P.S.) - By adding together the scores for the different exercises performed, the total score for each caregiver was established. Because the caregivers have differing numbers of exercises to perform, the average was then calculated by dividing the total score by the number of exercises performed. This was then defined as the average performance score (A.P.S.).

Cerebral Palsy - In this study the children evaluated had either been diagnosed as having cerebral palsy by doctors at Red Cross Children's Hospital, or present with symptoms characteristic of cerebral palsy.

Cerebral Palsy (C.P.) is a permanent impairment of posture and movement due to a non-progressive lesion or malformation of the brain

which exists from early childhood. Although the cerebral lesion is non-progressive, the clinical presentation is progressive due to exacerbated clinical features and associated deterioration over time. There are also a number of secondary manifestations which may occur. These include fits, mental retardation, visual and auditory impairment.^{47,48}

The different types of cerebral palsy are classified according to the presentation of the child, either with regard to the predominant motor tone or with regard to the involvement of the limbs. Firstly with regard to the predominant muscle tone:

- Spastic:** In which spasticity or hypertonia is the dominant motor tone and pattern.
- Hypotonic:** In which hypotonia is the dominant motor tone and pattern.
- Athetoid:** In which choreoathetosis and/or dystonia are the dominant motor pattern.
- Mixed:** In which features of both spasticity and athetosis are present.

Secondly with regard to the involvement of the four limbs, the following classification was used:

- Quadriplegia:** In which all four limbs are involved.
- Diplegia:** In which the legs are involved more than the arms, which may be normal.
- Hemiplegia:** In which one side of the body is affected.

Cognitive development - This involves the development of comprehension, communication, concentration, problem-solving, time management, conceptualization, integration of learning and judgement.⁵⁰

Community Based Rehabilitation - CBR is a range of methods that help support disabled children in their families and communities. It is not represented by one set of techniques or easy solutions. It should link with existing specialist services. It must also build on

the resources of the community, release the potential of disabled people and their families, while being sensitive to their expressed needs. (see Chapter 3.2.)

Community Health Worker Co-ordinators - This refers to an experienced community health worker who has been promoted to co-ordinate a number of community health workers in a certain area. Three community health worker co-ordinators were the interviewers who administered the major questionnaire.

Disabled children - Children are defined as less than 12 years of age on the 31.7.92. Disabled children are children who have difficulty with moving, seeing, hearing, thinking, behave strangely or have a combination of any of the above difficulties.

Evaluator - The person with overall responsibility for the evaluation and author of this report (M.L.). M.L. initiated the RW project in 1988, is responsible for the training of the RWs and is still involved in ongoing support and supervision of RWs and management of the project.

Exercises Remembered - The number of exercises the caregiver remembered to do compared to the number of exercises she was shown. This was used as an outcome indicator.

Interviewer - Person who administered the questionnaire.

Language Development - This was defined as the caregiver actively working for communication with the child. It may involve talking to the child, giving the child a chance to understand what is being conveyed and a chance to express thoughts or needs to others.⁵⁰ It may be verbal or non-verbal and can include mouth awareness,

imitation of sound, pointing to things in the environment and awareness of body parts.

Major Questionnaire - Questionnaire administered by the interviewers which involved questions to the mother of the disabled child.

Minor Questionnaire - Questionnaire administered by the therapists, where the major focus was on observing the caregiver perform the exercises with her child.

Mother/Caregiver - Only mothers were involved in responding to the major questionnaire. Nine women who were not mothers were involved in responding to the minor questionnaire. *Mother* will be used in responses to the major questionnaire and *caregiver* will be used in responses to the minor questionnaire.

Motor Development - Motor development was divided into gross motor development and fine motor development.

a) **Gross motor development** was defined as a movement or activity in which groups or large muscles or systems are involved.⁵⁰

b) **Fine motor development** was defined as a movement or activity in which discrete muscle groups or systems are used.⁵⁰

Old Exercises - This refers to exercises that were performed by the caregivers which were originally taught by the therapists to the caregiver and RW, but had been discontinued.

Primary Health Care - "Essential health care made accessible to individuals and families in the community by means acceptable to them, through their full participation, and at a cost that the community and the country can afford."²⁷

Progression of exercises - This refers to whether the exercises follow a meaningful sequence.

Rehabilitation - "Rehabilitation aims at reducing the impact of disability and handicap, so that the disabled and handicapped can achieve social integration. Rehabilitation involves training disabled and handicapped persons to adapt to their environment. It also involves intervening in the environment and society as a whole to facilitate social integration. The disabled and handicapped themselves, their families and the communities they live in should be involved in the planning and implementing of rehabilitation services."¹⁶

Rehabilitation Therapist/Therapist - This refers to either the occupational therapist or physiotherapists who work with SACLA.

Self Help Skills - These were defined as any attempt to develop personal care in any of the following ways: washing, eating, dressing, toilet training, brushing teeth, brushing hair, attempting to wipe his mouth if he drools and attempting to wipe his nose if it runs.

Socialization - It is through socialization that the child develops the ability to function within a group and accept the demands of the culture and society in which she lives.⁴⁹ For the purpose of the minor questionnaire socialization was defined as the caregiver making an attempt to interact with her child.

Taught exercises - This refers to the exercises taught by the SACLA therapists to the RW and the caregiver.

4.2. THE PURPOSE AND OBJECTIVES OF THE EVALUATION.

4.2.1. The Purpose of the Evaluation.

There were two purposes to this evaluation. The first concerned the service that the RW project is providing. After five years of field work there was a need to evaluate whether the goals of the project were being achieved, and to identify the strengths and weaknesses. By addressing the weaknesses it is hoped that the service will be streamlined, more effective and more sensitive to the needs of disabled children and their families.

The second purpose is on a broader scale. The SACLA RW project is one of a few RW projects in the country and it is often used as a model for RW projects. The value of the RW project needs to be established by an evaluation, so as to provide insights for other local RW projects.

4.2.2. The General Objectives of the Evaluation.

A. To evaluate the service in terms of the disabled child and mother.

The first main objective of this evaluation was to determine if these children have benefitted from the service. Due to the severity of the conditions seen, a major focus of the work is to support the prime caregiver (usually the mother), by visiting her regularly to provide emotional support, to inform her about the condition of her child and to teach her how to handle her child.

Thus the specific objectives were:

1. To develop a profile of the disabled children with cerebral palsy and their families.
2. To gain a better understanding of the mother's feelings about and attitudes to her disabled child, her understanding of the condition and the needs she and her child have as a result of the disability.
3. To hear from the mothers their opinion about the service the SACLA RW project provides and whether this has played a role in meeting the needs of the mother and her child.
4. To determine whether mothers preferred the hospital based service by physiotherapists to the home based service by RWs.

B. To evaluate the service from the point of view of the trainer.

The training of the RWs was developed by the evaluator based on her experience. There was a need to formally determine whether the training equips the RWs to meet the needs of the mothers in terms of caring for their children so that they develop to their maximum potential and provide emotional support for the mother.

Thus the specific objectives were:

1. To determine whether the caregiver knew the exercises that her child needs.
2. To evaluate how well the caregiver performed these exercises and activities with her disabled child.
3. To determine whether the child was treated holistically.

C. To evaluate the service from the point of view of the RWs.

There was no attempt to evaluate the service from the point of view of the RWs. This could be done at a later stage. It was not undertaken as the evaluation was already quite extensive. The areas which could be looked at are:

- How do the RWs feel about their work?

- How do the RWs relate to each other?
- How do the RWs relate to the disabled children and their caregivers?
- Do the RWs feel their training has equipped them to do the work they have to do?
- Is the support of the therapists and co-ordinators a real support?

4.2.3. Type of Epidemiological Study.

This was an evaluation study concerned mainly with outcomes in terms of:

1. Maternal understanding of the problem with her child and the aetiology and prognosis thereof.
2. Maternal opinion of the RWs and their work.
3. Caregivers performance of the exercises taught to them by the RWs.
4. Caregivers relationship to her child.
5. Establishing a profile of disabled children.

It is a cross sectional descriptive study with some analytical components.

4.3. STUDY POPULATION

4.3.1. Definition of Study Population.

The study population included all children treated by SACLA having a neurological condition which is cerebral in origin and a moving difficulty as a result of this. Other difficulties may also be present. The caregiver and child must live in the areas in which the SACLA rehabilitation project operates and had to be present in these

areas during November 1992 when the interviews were conducted. The caregiver and child must have attended the project services for at least four months and have seen the R.W. at least once during the four months prior to the evaluation taking place. It was also decided to include some children who were newcomers to the project for comparative purposes.

4.3.2. Reasons for Chosing this Study Population.

A. Cerebral palsy comprises the majority of children.

Data of the SACLA RW project indicated that the majority of the cases seen were neurological conditions, of which the most common was cerebral palsy.¹⁸ (see Chapter 1.2.9.)

B. Proportionally more time spent with children with cerebral palsy.

Children who have cerebral palsy and their caregivers form a major focus of the RW project and proportionally more time is spent with this group than with any other.

A child with cerebral palsy and a resultant spastic quadriplegia can take a lot of the RWs time as they are seen twice or even thrice a week, whereas a child with poliomyelitis is visited once every six weeks to ensure that no problems have arisen.

Thus it was thought that by interviewing the caregivers of these children the most accurate reflection of the service would be achieved. Both quantitative and qualitative data were wanted from the evaluation. It was thought that the caregivers with whom considerable time has been spent would be in a better position to

respond appropriately to the questionnaire than the people seen less often.

C. Relevance beyond SACLA.

Cerebral palsy is a major cause of disability in children in Africa.^{51.52.53} The condition of these children is often severe and their caregivers find themselves in desperate need of health services, welfare assistance and emotional support. The results of such an evaluation would therefore have a relevance beyond SACLA.

4.4. SAMPLING.

4.4.1. Sample size.

392 children had been seen in the RW project from the 1 August 1989 - 31 July 1992.¹⁸ Due to the constant migratory and cyclical movement of so many people in the areas in which SACLA works, the number of children with cerebral palsy being actively seen by the RWs at the time of the study was 96. It was decided that 50 was a feasible number for the sample size, given the limited resources, time and the fact that this was the first study done within the RW project. It was a preliminary study and future studies based on this will be possible. It was felt that a sample size of less than 30 would be too small.

It was decided that 40 would be children who had been involved in the RW project for longer than four months and ten would be newcomers. In the end, however, only eight newcomers were seen.

4.4.2. Method of Sampling.

There are nine RWs in the project. Each one sees a different number of disabled children. For the sample to represent the study population as accurately as possible, sampling was performed by proportional stratified random sampling. This was used to increase confidence in making generalizations to particular areas, as RWs work in defined geographical areas.⁵⁴

The proportional stratified random sampling was done in the following way for the 40 longer term children.⁵⁵ Firstly, the following formula was used to determine the percentage of active cases that each RW sees:

$$\frac{\text{Active No. of Cases for RW n.}}{\text{Total No. of Active Cases}} \times 100 = y\%$$

eg. for RW no.1 $\frac{13}{96} \times 100 = 13\%$

Secondly, as 40 was the desired number of cases, to get a proportional representation of 40 for each R.W. the following formula was used:

$$\begin{aligned} \text{eg. } x/40 &= 13\% \\ \text{so } x &= 13 \times 40/100 \\ &= 5 \text{ people for RW no. 1} \end{aligned}$$

The same formula was used for the ten newcomers, and the final sample of 50 was chosen using a random number table.⁵⁵

4.5. DATA COLLECTION.

4.5.1. Development of the Questionnaire.

Having decided that the measuring tool for the evaluation would be a questionnaire, a number of questionnaires used to evaluate primary health care and community based rehabilitation projects were studied to get an idea of the type of questions, how they were asked and the format used.^{30,44,45} The questionnaire that was used as a starting point was that used by *Save the Children Fund* in their evaluation of the Community Based Rehabilitation programme of the organization of disabled people of Zanzibar in October 1989.³⁰

A rough draft of the questionnaire was then evaluated by a number of people including some who work within the area of primary health care: a doctor in the organization, a social anthropologist, people involved with research, an epidemiologist, and a researcher with experience in qualitative and primary health care research. Their comments were taken into account and the questionnaire adjusted accordingly. After a number of drafts, the questionnaire divided into two main sections:

1. Questions to the mother of the disabled child about her feelings and needs, as well her experience of the SACLA rehabilitation project.
2. Observing how the prime caregiver (usually the mother) handles, plays, treats and performs activities with her child including those shown to her by the RW.

4.5.2. Choice of People to Administer the Questionnaire.

As indicated above, the questionnaire fell into two main sections:

1. Questions to the mother. (Section 1)
2. Observation of the caregiver performing activities with the disabled child. (Section 2)

These two sections required people with different skills. To interview the mother (section 1) a Xhosa speaking person (interviewer), who inspired confidence and a willingness to talk is essential, but who is also literate and could read and fill in a questionnaire easily. To observe a person handling a disabled child, (section 2) required a person who has experience of handling, treating and working with cerebral palsied children, such as a rehabilitation therapist.

A. The Interviewers

Initially it was thought that to ensure minimal bias, a person from outside SACLA organization would have to be employed to interview the caregivers. A person from another health organization was considered.

After much thought it was decided that SACLA staff from a different part of the organization, not involved in the rehabilitation project at all, would be trained as the interviewers. The reason for this were:

1. SACLA Health Project, including the rehabilitation project, is highly regarded in the Western Cape as a model of primary health care. There was concern that an outside interviewer might put SACLA on a "pedestal", and miss some of the negative feelings expressed by the caregivers about the RW project.
2. There has been very little exposure to research at SACLA. If interviewers from SACLA were introduced to research and taught some elementary research skills, these could at a later stage be used elsewhere in the project.

The Community Health Worker Co-ordinators were asked if they would be prepared to assist the RW project in the evaluation for a number of reasons:

- a) They have very little to do with the RW project, so they would not be biased.
- b) They are literate, and could easily fill in an evaluation form.
- c) They co-ordinate community health workers in different areas, being responsible for their support, ongoing training and supervision. They are acutely aware of the problems of the CHW project, many of which are similar to those experienced in the RW project. It was felt that this heightened sensitivity would enable them to follow up problems hinted at by the caregivers during the interviews.
- d) They work in defined areas, so to avoid the possibility of them knowing the people they were interviewing they would interview in areas in which they did not work.
- e) As the co-ordinators are SACLA employees there would be no additional cost to the organization.

A meeting of the co-ordinators and the evaluator was called. At this meeting the need for interviewers was explained to the co-ordinators as well as the reasons why it was felt that they would be suitable to administer the questionnaire. They expressed interest and a willingness to be involved. They also wanted an opportunity to learn research skills which could be used in their work to evaluate the work of the community health workers whom they co-ordinate.

A date was set for a day long workshop with the co-ordinators (Appendix F). All the co-ordinators wanted to be involved in the workshop as a learning experience. After the workshop the co-ordinators chose from amongst themselves the interviewers to administer the questionnaire.

Initially it was thought that two co-ordinators should be involved in interviewing. After discussion with the co-ordinators it

was agreed that three co-ordinators would be interviewers for the following reasons:

- a) the disabled children and their caregivers live in three broad geographical areas.
- b) the co-ordinators felt that if three interviewers were involved it would only take up one week of their time. This would be easier for them to organize in terms of their workload. (As it was, all three co-ordinators were involved in doing interviews for two weeks).

B. The Therapists.

Initially it was thought that a therapist from outside the organization would have to be employed. This therapist would go around with the interviewer. The interviewer would first ask the caregiver the questions and at the end the therapist would ask the caregiver to demonstrate how she handles and treats her child.

However, this would have taken considerable time and much of the therapists' time would have been spent waiting for the interviewer to complete her section of the questionnaire, which seemed wasteful and an inefficient use of time.

In addition few therapists have had exposure to community based rehabilitation so that other issues, unrelated to the evaluation may get in the way. For example an "outsider" may negatively judge the choice of exercises (which is not being evaluated here) rather than determining the extent to which the caregivers were able to perform them. It was then decided to use the rehabilitation therapists within the project, two physiotherapists and one occupational therapist. It was felt that this would increase the validity of the evaluation as the therapists who work in the project are involved in deciding what is to be taught to the caregiver and teaching the treatment or exercises to both the RW and caregiver. Thus consistent

standards would be maintained throughout the project during the evaluation.

4.5.3. Translation of the Questionnaire Administered by the Interviewers.

Once the questionnaire for the interviewers was finalized, it was translated into Xhosa by the rehabilitation co-ordinator. To check the translation, it was translated back into English by a different person. Further minor changes were made to ensure clarity, after the training workshop with the co-ordinators.

4.5.4. Questionnaire Administered by the Interviewers.

The questionnaire administered by the interviewers will henceforth be referred to as the *major questionnaire* (Appendix C). Only mothers were interviewed for the major questionnaire as a number of questions related to the mother's feelings about her disabled child were asked. The objectives of the major questionnaire were noted in section 4.2.2.A. The questionnaire was divided into the following sections:

- A: Introduction.
- B: To determine the caregiver's attitude to the RW.
- C: To determine the caregiver's understanding of the problem with her child.
- D: To find out the mother's feelings, attitudes and needs.
- E: Observation by the interviewer.

A: Introduction (Questions A:1-4) The aim of the introduction was to find out who the prime caregiver of the child was, maternal age, the number of people living in the house and whether the father was present or not.

B: To determine the mother's attitude to the RW (Questions B:1-12)

In this section the mother was asked one word answer questions

(1,2,3,5,7) to determine if she knew the RW, the organization that the RW works for and how long the RWs visits were. A number of open ended questions (4, 8-12) were also asked to find out in more depth the caregiver's experience of the RWs visits.

C: To determine the mother's understanding of the problem with her child. (Questions C:1-4) In this section open ended questions were asked to determine the mother's understanding of the problem and prognosis of her child.

D: To find out the mother's feelings and needs. (Questions D;1-17) Here open ended questions (4,5) were asked to determine whether the mother perceived that both she and her child have specific needs related to the problems of the child's disability. She was also asked about her feelings for her child, to try and gain some understanding of how mothers have come to a point of accepting their child's condition (1,2,3) and whether the RWs have played a role in this. (6,7)

One of the questions asked was *In what ways has the RW helped you, if any?* This was asked in order to get an indication of whether the caregivers felt that the RWs had assisted them either by referring them to other health or welfare services, by teaching exercises, by supporting them or by giving advice. The interviewers were asked to note if the caregiver volunteered the information spontaneously or only on being prompted. This was done as mothers who responded without being prompted are very clear about how the RWs have helped them, whereas caregivers who have to be prompted may respond as they feel they have to, so the results are not necessarily as valuable as those which are unprompted.

In a peri-urban area there are a number of different health and service organizations. Activities are co-ordinated sketchily. In question 8 the mother was asked if the child had been seen by other services and who provided them.

Most of the children seen by the RWs are seen by physiotherapists at a tertiary level hospital in Cape Town. In questions 9 - 12 the mothers were asked to compare the way they and their child are related to by the RWs and these physiotherapists.

Question 12 was an attempt to discover if a lack of co-ordination between a number of health and service providing organizations is leading to confusion amongst the mothers. Questions 13 - 16 were questions also asked by the therapists. In question 13 the mother was asked to prioritize the treatment, handling and activities she does with her child. Questions 14, 15 and 16 were an attempt to find out if this treatment, handling and activities were a priority for the mother. Question 17 was an open ended question asking the mother for general comments about the SACLA rehabilitation project.

E. Observation by the interviewer. (Questions E:1-5) The interviewer was asked to observe the well-being of the child and the relationship between the mother and child.

4.5.5. Questionnaire Administered by the Therapists.

This will be referred to as the minor questionnaire (Appendix D), and the objectives are identified in Section 4.2.2.B. It was designed for the use of the therapists. The respondents to the minor questionnaire were not always the mother, but the person who was the prime caregiver at the time. To assist the therapists in filling in the minor questionnaire a help sheet was drawn up to remind them of the discussions and decisions reached (Appendix E).

In the first part of the minor questionnaire (*questions A: 1,2 and 3*) the therapist was asked to observe the well-being of the child and the way in which the caregiver related to the child.

Question A:4 had two aims. The therapists had to:

1. Observe how the caregiver treats, handles and positions her child.
2. Grade whether the activities she does with her child are relevant and how well they are done.

The therapists were asked first to describe the position in which the activities were undertaken and note any problems with this position. They then described the activities.

The relevance and effectiveness of the treatment, handling and activities was graded and standardized according to the table on page 82.

The aim of *question A:5* was for the therapist to observe whether the child was being treated holistically, i.e. was the child being treated as a human being and involved in the activities, or was the child being treated as a passive object on whom a routine set of exercises were being performed.

Firstly, it was decided to look for the caregiver attempting to interact and relate to the child both at the level of the child, but also challenging the child to respond at a higher level. Secondly, the therapists were asked to observe whether a number of different aspects of the child's development were stimulated during the time that the caregiver was busy with the child and how these were stimulated. The different areas that were considered to be significant and needing stimulation were socialization, language development, motor development, self help activities and cognitive development. (An evaluation of a CBR programme in Vietnam chose similar foci³³).

For both gross and fine motor development the therapists were also asked to grade the child's involvement according to the following 3 levels:

SCORING CRITERIA FOR CHILD'S INVOLVEMENT IN ACTIVITIES

1. Passive - Caregiver doing the activity on the child with no interaction with the child.
2. Caregiver and child - Caregiver's activity with the child involved, although he might not be able to do the exercise in any way.
3. Child active - The caregiver gives the child a chance to actively respond. She gives him time to respond.

The aim of section B was to determine whether the caregiver regards the treatment, handling and activities shown to her by the RW as a priority. The caregiver was asked whether she thought the exercises were important and why (in relation to the child) and how often she did these exercises.

4.5.6. Variables to be Measured.

4.5.6.1. Outcome Indicators.

Each RW and caregiver were taught a number of exercises by the therapist. An important role of the RWs is to ensure that the caregiver knows these exercises and carries them out at home. The performance of the caregivers was therefore used as an indication of the success or failure of the project. Six different outcome indicators were used to evaluate the performance of the caregiver. A number of exposure variables were examined in relation to each outcome indicator to determine if they had any significant influence

upon the outcome indicators. The six outcome indicators will now be described:

A. Average Performance Score (A.P.S.).

One of the objectives of the evaluation was to evaluate how well the caregiver performs the exercises and activities she has been shown by the RW with her disabled child. For the evaluation the caregivers were asked to demonstrate to the therapist the exercises that they do with their child. The therapist observed these and gave the mother a score for each exercise, deducting points for an ineffective exercise, incorrect positioning, incorrect handling or execution of the exercise or activity. The A.P.S. was then deduced from these scores, and scores above the median (4.25) were considered to be "high".

SCORING CRITERIA FOR CAREGIVER'S TREATMENT PERFORMANCE

- 5 - Activity relevant and carried out with maximum effectiveness. (*almost perfect*)
- 4 - Activity relevant, but one thing wrong which compromised effectiveness. (*very good*)
- 3 - Activity relevant, but 2 things wrong which compromised effectiveness. (*good*)
- 2 - Caregiver had the general idea of the activity, but 3 things wrong, so it is questionable that the child would have benefitted from the activity. (*inadequate*)
- 1 - Activity very poorly done and of no benefit. (*poor*)
- 0 - Caregiver had no clue about activity at all. (*useless*)

B. Exercises Remembered.

Each caregiver was evaluated on her knowledge of the activities needed by her child that is, exercises remembered. In the analysis those who remembered all the exercises were compared with those who forgot one or more exercises.

C. Were the Children Related to in a Holistic Way?

A third objective related to the performance of the caregivers was to determine whether the child was treated holistically. The therapists were thus asked to observe whether the caregiver stimulated the child in a number of different areas. On a social level, did she interact with the child (socialization), did she stimulate language development, did she facilitate motor development, self help skills and cognitive development.

For all these behaviours the therapists were asked to observe if they were present or not and then to describe the activity and what the behaviour was. Responses were grouped together in themes and coded. In addition, motor development was divided into gross and fine motor development and the therapists were asked to grade the level to which the child was involved in the activity.

D. Prioritizing Exercises.

In the major questionnaire the mother was not asked to demonstrate the exercises, positions and handling she did with her child, but to show the interviewer the two activities which are most important for her child. The interviewers were asked to describe these. The ability to prioritize exercises implies an understanding of the major problems that the child has. This was compared to the treatment plan

noted on the therapists notes for the child. For the bivariate analysis data was based on the caregivers who could prioritize both activities. The scoring criteria used were as follows:

CRITERIA FOR SCORING THE PRIORITY OF EXERCISES

- 0 = Neither activity demonstrated is a priority
- 1 = One activity demonstrated is a priority
- 2 = Both activities demonstrated are priorities

E. Progression of Exercises.

To determine whether exercises were progressed, the exercises that were demonstrated by the caregivers were analyzed to see if the sequence was logical or not.

4.5.6.2. Exposure Variables.

Six different exposure variables were chosen to determine whether they influenced the outcome indicators significantly. These exposure variables were:

- a) the age of the child
- b) the age of the mother
- c) the identity of the prime caregiver
- d) the status of the child - which refers to the length of time the child has been involved in the project
- e) the presence of the father
- f) the number of people living in the shack.

4.5.6.3. Mother's Attitude.

The mother's attitude on a number of issues was measured against the outcome indicators identified above (4.5.6.1.) to determine to what extent her attitudes affected her performance. Where the caregiver was not the mother the results were not considered.

A. Mother's attitude towards her child. Two variables were measured in this category:

- a) Mother's level of hope
- b) Mother's present feelings about her child

B. Mother's attitude towards the RW. Two variables were measured in this category:

- a) Perceived duration of the RWs visits.
- b) Perceived frequency of the RWs visits.

4.5.6.4. Added Exercises

In comparing the performance of the caregiver, taught exercises and added exercises were compared, with the added exercises used as an indicator for contamination.

A comparison between the performance score of added and taught exercises raises important issues about the relationship of the SACLA RW project to other organizations. The different sources from where added exercises came and the different scores that were given to them were looked at.

4.6. VALIDITY OF THE DATA.

4.6.1. Structural Attempts to Ensure Validity of Data.

In an attempt to avoid a positive bias the minor questionnaire was **incorporated into the work routine** of the therapists. It was administered to all disabled children seen by the therapists on their regular morning training and supervision sessions for a six week period from the 1 November to the 15 December. It was started before the sampling was done. Two of the therapists had no idea which children were chosen specifically for the evaluation. The third therapist (the evaluator) knew who the children chosen for the evaluation were midway through November when over half of the children needing to be interviewed by the therapists were completed.

In an attempt to minimize the chance of them knowing the people whom they interviewed, the interviewers were **assigned to interview in an area different** to their area of work or residence.

Emphasis on training: During the training workshop for the interviewers the importance of writing observations and responses down immediately was emphasized. The questionnaires were filled in in Xhosa and translated at a later stage. **Close supervision was done on a daily basis.** Each morning the completed questionnaires were checked and where possible, gaps filled in. Difficulties which had arisen the previous day were discussed so as to avoid them recurring. The importance of filling in each question was emphasized again each morning. Each interviewer translated her own interviews.

4.6.2. Overlap in the Questionnaires.

The observation by the therapist of the child's well being and how the caregiver related to the child were also included in the major questionnaire administered by the interviewers. This duplication of questions was intentional and was an attempt at checking for consistency. It was feared that a special effort may have been made by the caregiver for the professional therapists who also happened to be white.

Observations of the caregiver's interactions with the child were included in both the major and minor questionnaires. This was also done to check for consistency. The questions asked by the therapist concerning how often the caregiver does activities, whether she feels they are important or not and what they do for her child were also asked by the interviewer.

4.7. PILOT STUDIES.

4.7.1. Piloting the Major Questionnaire.

This was done by the CHW co-ordinators as part of the training workshop for administering the questionnaire. Seven co-ordinators and one therapist were involved in this workshop. At the workshop two people volunteered to role-play an interview. The questionnaire was worked through and changes made.

After this the CHW co-ordinators divided into pairs. Each pair went out into the community and interviewed a caregiver with a child who had poliomyelitis. Four mothers with their children were interviewed. After this further necessary changes were made to the major questionnaire.

4.7.2. Piloting the Minor Questionnaire.

Once an initial draft of the minor questionnaire was drawn up, the three therapists met to discuss this and work out scoring criteria to grade the relevance and effectiveness of the treatment, handling and activities performed by the caregivers. Changes were made where necessary. Each therapist then piloted the questionnaire with two caregivers during one of the morning sessions with a RW in the course of the following week.

One of the problems that arose in the piloting of the questionnaire was how to standardize the grading for the relevance and effectiveness of the treatment, handling and activities. In an attempt to standardize the grading, the therapists together watched a mother treating her child. Each therapist recorded how the mother treated, handled and performed activities with her child and scored the relevance and effectiveness of these according to the scoring criteria drawn up. Considerable time was spent together developing common definitions and standardizing the scoring.

4.8. LOGISTICS.

4.8.1. Time-Plan.

July 1992 - Protocol for evaluation submitted to UCT.

August 1992 - Protocol accepted by the UCT Medical Facility.

First week of October 1992 - Questionnaires drawn up, circulated for opinions and necessary changes implemented.

2nd week of October 1992 - Translation of major questionnaire.

Training workshop with interviewers.

3rd week of October 1992 - Major and minor questionnaires piloted and grading system developed

4th week of October 1992 - Questionnaires finalized and printed.

1 November 1992 - Therapists started administering minor questionnaire routinely.

Second week of November 1992 - Sample drawn.

Third week of November 1992 - Interviewers started administering the major questionnaire.

15 December 1992 - Evaluation forms completed and translated.

January and February 1993 - Analysis programme decided upon.

Beginning with the write up.

March 1993 - Data entered onto a personal computer at home and analyzed.

April 1993 - First draft of results written up and further analysis undertaken.

May 1993 - A workshop held informing the RWs of the results of the evaluation.

June 1993 - Feedback of results to SACLA at a general staff meeting. Literature review written up.

July 1993 - Two more workshops to be run with the RWs feeding back more results and implementing some of the changes highlighted by the evaluation. A report of the evaluation sent to the funders of the project, the Henry Kaiser Foundation from Washington, USA and Warner Lambert, based in Cape Town.

4.8.2. Data Collecting Schedule.

The evaluator drew up a plan of which disabled children were to be visited each day and which RWs would be working with the interviewers for that day. Each morning the evaluator fetched the three interviewers.

Before setting out a discussion took place in the car about the previous days interviews and problems were sorted out. The evaluator went through the forms to check that there were no unanswered questions and gave the interviewers the numbers of the houses and the children to be visited on this day and the questionnaires filled in with basic information about each child.

The evaluator then fetched the RWs scheduled to work with the interviewer that day. The RW and interviewer were taken to one of the houses they needed to visit that day. The RW went into each house with the interviewer, introduced her and then left returning an hour later to take her to the next house to introduce her there.

The interviewers spent from 9.00 - 15.00 interviewing and after this translated the answers into English. Within eight working days the majority of the interviews are conducted, but the few outstanding interviews took a further week and a half to complete.

4.9. PRACTICAL CONSIDERATIONS.

4.9.1. Analysis.

The completed questionnaires were entered into a personal computer on EPI INFO. The results were analyzed using univariate and bivariate analyses. Assistance with the analysis of data was obtained from the Centre for Epidemiological Research in South Africa (CERSA).

Qualitative results were written up from notes taken by the facilitator during the feedback session to the RWs.

Bivariate analyses were done on a number of occasions:

A. Holistic treatment of the child.

For the bivariate analyses socialization and language development were chosen as outcome indicators for the holistic treatment of the child. These two categories were chosen as the caregivers performed very differently in these two categories.

In the bivariate analysis caregivers who did not include socialization or included it minimally were compared to those who scored well. In language development those who included language development were compared to those who did not.

B: Outcome indicators and exposure variables.

Bivariate analysis using the chi squared test was done comparing the different outcome indicators with six chosen exposure variables (listed in section 4.5.6.2.).

C: Added and taught exercises.

Bivariate analysis using the chi squared test was done to see if there was a significant difference between the scores of added and taught exercises.

D. Average performance score and the number of exercises remembered.

To compare the different RWs the average performance score and number of exercises remembered by the caregivers were used and bivariate analysis was done using the chi squared test.

4.9.2. Resources.

For the past four years the SACLA RW project has been funded by the Henry Kaiser Foundation. After an initial grant of three years they hesitated before funding the project again and said an evaluation of the project needed to be undertaken. Accordingly R 1000 was added to the budget in order to evaluate the project.

People from within SACLA were used to do the evaluation so that there were no travel costs or extra payment of personnel involved. No equipment was used and all computer work was done on the personal computer of the evaluator. Thus visible costs incurred to the project were stationary, photostating, transport costs and personnel time.

It can be seen that the extra costs of the evaluation were not large. However, the hidden costs of the evaluation in terms of the salaries of the staff involved and the time it took were considerable. It is difficult to quantify these, but the hidden costs of this evaluation ensure that it was not a cheap evaluation.

4.9.3. Ethical and Legal Considerations:

The proposal for the evaluation was passed by the UCT ethics committee. The evaluator in taking responsibility for the evaluation undertook to ask SACLA organization, the RWs and the caregivers if they felt the evaluation was appropriate and were prepared to be involved in it. She also undertook to feed back as much necessary information to these groups as would be possible. The questionnaires were treated as confidential information.

A number of sensitive issues were raised in the interviews. The interviewers were equipped with counselling skills and could refer any problems they did not feel able to deal with to the evaluator.

4.9.4. Reporting of the Data.

The SACLA RWs and therapists were informed of the results at three workshops. Suggested changes highlighted by the evaluation were addressed in workshops attended by all the workers of the RW project.

The rest of SACLA was informed of the results of the evaluation on the 24th June at a General Staff Meeting. A written report of the results will be filed at the project.

The mothers and caregivers will be informed of the results at two workshops, one in the Khayelitsha area and one in the New Crossroads area. Having two workshops in the different townships should make it possible for mothers in the different areas to attend.

CHAPTER FIVE: RESULTS

In this chapter the results of the questionnaires are discussed. In those few instances where it explains and gives more depth to the quantitative data, the qualitative data has been included.

5.1. A PROFILE OF THE DISABLED CHILDREN AND THEIR FAMILIES.

5.1.1. Geographic Distribution and Living Conditions.

The disabled children who participated in the evaluation live in eight different areas, with the majority coming from Khayelitsha. 43 (90%) of these children live in shacks. Tables 5.1.1.A. and 5.1.1.B. set out the different areas from which these children come and the type of houses they live in. The median number of people living in a dwelling in this study is 6 (Graph 5.1.1.C). A back shack refers to a second shack on the property built behind the house of the legal owner.

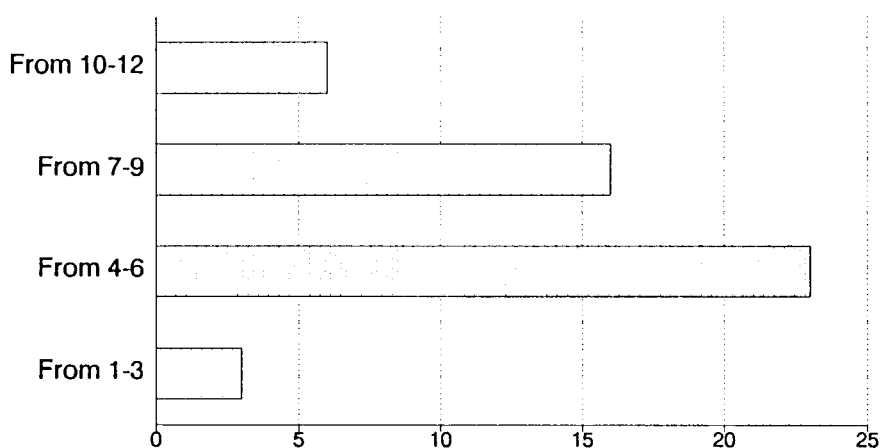
TABLE 5.1.1.A. AREAS WHERE DISABLED CHILDREN LIVE.

| Place | Number of People | Percentage |
|---------------------|---------------------|------------|
| Khayelitsha: | 37 | 77% |
| Site B | 14 | 29% |
| Site C | 16 | 34% |
| Harare | 4 | 8% |
| Makaza | 2 | 4% |
| Town Two | 1 | 2% |
| KTC | 3 | 6% |
| New Crossroads | 5 | 11% |
| Browns Farm | 3 | 6% |
| Total | 48 | 100% |

TABLE 5.1.1.B. DIFFERENT TYPES OF HOUSES.

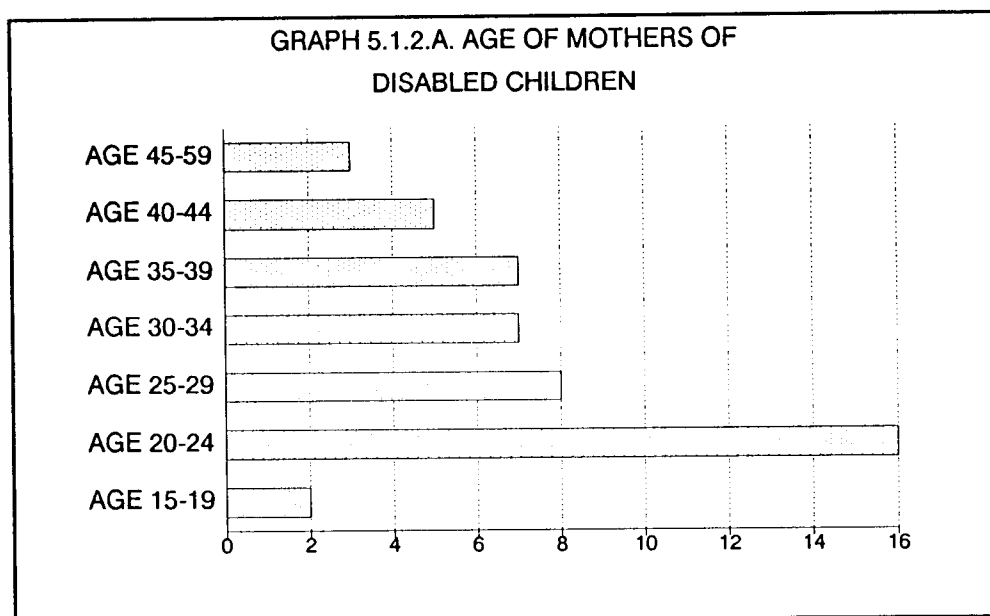
| Types of Houses | Number of People | Percentage |
|-----------------|------------------|------------|
| Shacks | 43 | 90% |
| Serviced | 20 | 42% |
| Unserviced | 22 | 46% |
| Back | 1 | 2% |
| Formal dwelling | 5 | 10% |
| Total | 48 | 100% |

GRAPH 5.1.1.C. NUMBER OF PEOPLE LIVING IN EACH HOUSE



5.1.2. Parental and Primary Caregiver Characteristics.

31 (65%) of the children had their father living with them. The median age of the mothers of these children was 28 (Graph 5.1.2.A).

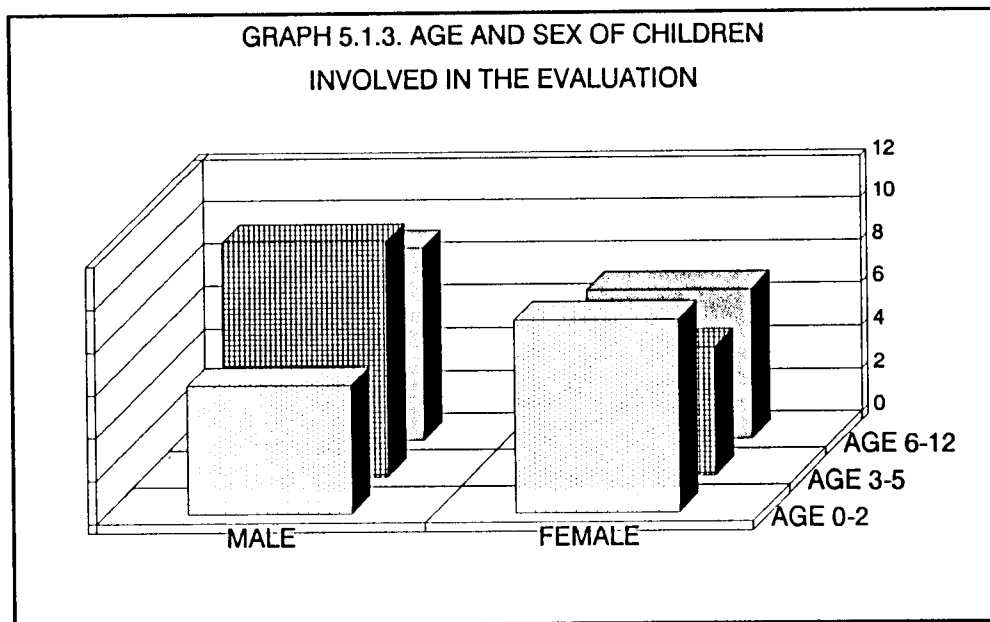


43 (90%) of the adults spoken to and taught exercises by the RWs were the mothers. At the time of this study 39 (82%) of the children were looked after by their mothers (Table 5.1.2.B.).

| TABLE 5.1.2.B. PRIMARY CAREGIVER COMPARED TO PERSON EDUCATED BY SACLA RW. | | | | | |
|--|-------------------|------|-----------------|------|--|
| | Primary Caregiver | | Person Educated | | |
| Mother | 39 | 82% | 43 | 90% | |
| Grandmother | 4 | 8% | 4 | 8% | |
| Other family | 3 | 6% | 1 | 2% | |
| Support Group | 2 | 4% | 0 | 0% | |
| Total | 48 | 100% | 48 | 100% | |

5.1.3. Age and Sex of Children.

Graph 5.1.3. shows that 26 (54%) of the sample were boys and 22 (46%) were girls. There were almost twice as many boys in the 3 - 5 year category. There were no significant differences in the other age categories.



5.1.4. Type and Aetiology of Cerebral Palsy.

The type and aetiology of cerebral palsy in the disabled children used in the sample is set out in Tables 5.1.4.A. and 5.1.4.B.. The type of cerebral palsy is based on the diagnoses of doctors who run the Development and Assessment and Cerebral Palsy clinics at Red Cross Children's Hospital and in the cases of children who have not been seen at Red Cross, the rehabilitation therapists based at SACLA. The largest single group of children (22 or 46%) were diagnosed as having spastic quadriplegia. The table showing the different aetiologies indicates the high proportion of perinatal causes of cerebral palsy (21 or 43%).

TABLE 5.1.4.A. TYPES OF CEREBRAL PALSY

| Type | Number | Percentage |
|----------------|-----------|------------|
| Spastic | 31 | 64% |
| Quadriplegia | 22 | 46% |
| Diplegia | 4 | 8% |
| Hemiplegia | 5 | 10% |
| Hypotonic | 7 | 15% |
| Athetoid | 5 | 10% |
| Mixed | 3 | 7% |
| Other | 2 | 4% |
| Total | 48 | 100% |

TABLE 5.1.4.B. AETIOLOGY OF CEREBRAL PALSY

| Aetiology | Number | Percentage |
|--------------------------|-----------|------------|
| Prenatal | 7 | 15% |
| Perinatal | 21 | 43% |
| Asphyxia | 13 | 27% |
| Prematurity | 3 | 6% |
| Neonatal Jaundice | 4 | 8% |
| Other | 1 | 2% |
| Postnatal | 20 | 42% |
| TB Meningitis | 5 | 11% |
| Bacterial Meningitis | 3 | 6% |
| Cerebral Vein Thrombosis | 3 | 6% |
| Encephalitis | 1 | 2% |
| Unknown | 8 | 17% |
| Total | 48 | 100% |

5.2. MATERNAL UNDERSTANDING AND ATTITUDES.

5.2.1. Maternal Perception of her Child's Problem and the Aetiology and Prognosis thereof.

The mothers' perception of their children's problem is in Table 5.2.1.A. The responses of the mothers fell into three categories. They defined the problem by function, symptoms or aetiology. The majority of the mothers do not have a clear understanding of the condition and prognosis of their disabled child as can be seen from the responses in Table 5.2.1.B. One mother thought that her child had poliomyelitis. This may be an extreme example, but the following five tables are an indication that mothers are not well informed. 11 (23%) of the mothers said that they did not know why their child had a problem. One mother said in response to the question as to why her child has a problem:

The doctor said 23 things build up a child and this child has the 9th one absent.

TABLE 5.2.1.A. MATERNAL PERCEPTION OF THE CHILD'S PROBLEM

| Mother's Perception | Frequency | Percentage |
|--------------------------------------|-----------|-------------|
| Defined by Function | 17 | 35% |
| Child unable to do certain things | 15 | 31% |
| Child cannot do anything for herself | 2 | 4% |
| Defined by Symptoms | 16 | 33% |
| The child is lazy | 5 | 11% |
| Child is stiff | 3 | 6% |
| The child has fits | 3 | 6% |
| Child has poor balance | 2 | 4% |
| Child is floppy | 2 | 4% |
| Child is ill | 1 | 2% |
| Defined by Aetiology | | |
| A problem with the brain | 10 | 21% |
| Don't know | 5 | 11% |
| Total | 48 | 100% |

TABLE 5.2.1.B. MATERNAL UNDERSTANDING OF THE AETIOLOGY.

| Reason for problem | Frequency | Percentage |
|-----------------------|-----------|-------------|
| Problem during labour | 13 | 28% |
| Don't know | 11 | 23% |
| Fitting | 9 | 19% |
| Brain damage | 5 | 10% |
| Meningitis | 5 | 10% |
| Born like this | 4 | 8% |
| Poliomyelitis | 1 | 2% |
| Total | 48 | 100% |

From Table 5.2.1.C. it can be seen that only one mother expressed that she had no hope for her child. 29 (61%) of the mother's expressed the hope that their child would be better in a years time.

TABLE 5.2.1.C. MATERNAL UNDERSTANDING OF THE PROGNOSIS

| Mother's responses | Frequency | Percentage |
|---|-----------|------------|
| Child will improve | 29 | 61% |
| Child will be better | 23 | 48% |
| I hope he will be better | 6 | 13% |
| Conditional improvement | 6 | 12% |
| Child will be better if he can have regular exercises | 5 | 10% |
| If she stops fitting she will be better | 1 | 2% |
| Child will stay the same | 8 | 17% |
| Child will be the same | 7 | 15% |
| I have no hope | 1 | 2% |
| Don't know | 5 | 10% |
| Total | 48 | 100% |

TABLE 5.2.1.D. MATERNAL PERCEPTION THAT CHILD WILL ATTEND A NORMAL SCHOOL (A SCHOOL WHICH IS NOT A SPECIAL SCHOOL.)

| Mother's responses | Frequency | Percentage |
|--------------------|-----------|------------|
| No | 30 | 63% |
| Yes | 12 | 25% |
| Others | 3 | 6% |
| I don't know | 3 | 6% |
| Total | 48 | 100% |

30 (63%) mothers responded that their child would not be able to go to a normal school and would have to go to a special school (Table 5.2.1.D.). Two characteristic responses were:

I don't think so, maybe God can help her.

I hope and pray she will go to a normal school.

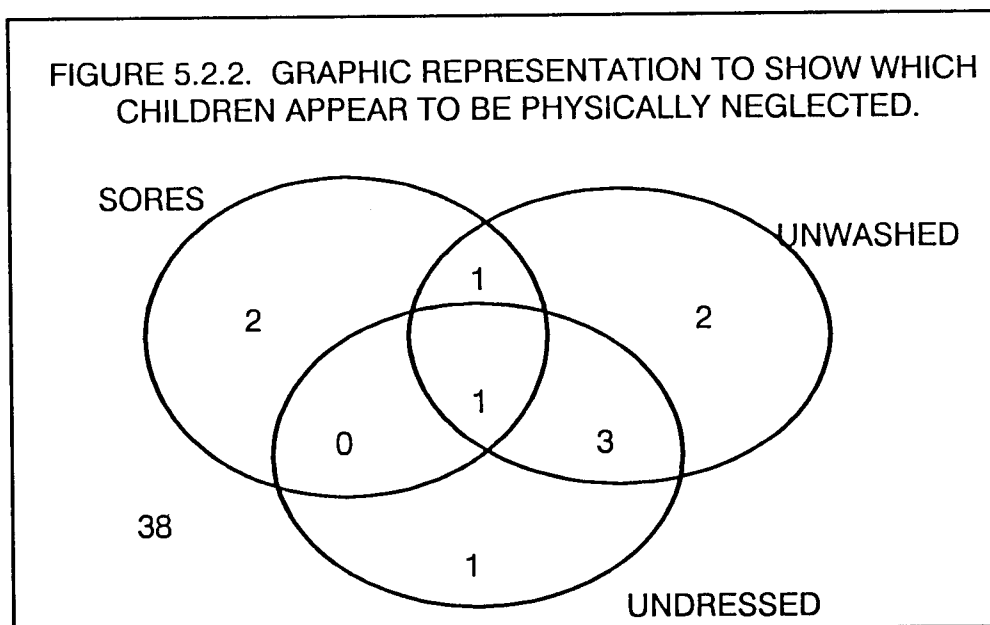
When asked if the mothers had any needs because of their disabled children, 43 (90%) mothers stated something material and seven mothers said that they had no special needs. 22 (46%) of the mothers said they needed financial assistance in the form of a grant and a

further 8 (17%) mothers said they needed someone to look after their child so that they could go out to work to earn money for themselves and their child. In Table 5.2.1.E. it can be seen that 35 (73%) mothers identified specific needs for their disabled children.

| TABLE 5.2.1.E. MATERNAL PERCEPTIONS OF THE NEEDS OF THEIR DISABLED CHILDREN. | | |
|--|-----------|-------------|
| Mother's responses | Frequency | Percentage |
| Has needs | 35 | 73% |
| Material assistance, grant, pram, wheelchair | 15 | 31% |
| Yes | 11 | 23% |
| Exercises | 3 | 6% |
| A special school | 6 | 13% |
| Has No Needs | 10 | 21% |
| Don't know | 3 | 6% |
| Total | 48 | 100% |

5.2.2. Observations of the Mother's Physical Care or Neglect of her Child.

In Graph 5.2.2. the interviewers observed that seven children were unwashed, five children were undressed and four children had sores.



One child was observed to be both unwashed, undressed and have sores. One of the interviewers noted in observing one of the children who was not washed that:

....the mother was very young and also had two step-children to look after.

Another interviewer also noted in observing a child who was not washed that:

The mother hasn't got time because she was getting in and out, because she was cooking beer and even getting information from her was too difficult as she was so busy.

5.2.3. Observation of the Interaction between the Mother and her Disabled Child.

These results were based on the interviewers observations. These were felt to be more valid as the interviewer was with the child for much longer and most of this time was spent talking to the mother so there was much time to observe how she interacted with her child.

The results of the interviewers and therapists were not significantly different when the chi squared test was done.

From Table 5.2.3. it can be seen that most of the mothers were observed interacting positively with their children, The interviewers also included comments such as:

The child loves his mother, he keeps putting his arms around her and kissing her.

The mother is very gentle with her child.

The mother holds him tight when he is miserable.

She is very accepting of her disabled child.

In total 7 (3.6%) negative interactions were made compared to 181 (96.4%) positive interactions. Thus only one in 25 of the interactions observed were negative. It can be concluded that mothers interact positively with their disabled children most of the time.

TABLE 5.2.3. OBSERVATIONS OF MOTHER'S INTERACTIONS WITH HER CHILD.

| Mothers actions during interview | Frequency | Percentage |
|---|------------|--------------|
| Positive Interactions with child | | |
| Talked to her child | 39 | 22% |
| Made eye contact | 23 | 12% |
| Touched her child | 33 | 18% |
| Kissed her child | 29 | 15% |
| Took time with her child | 40 | 21% |
| Handled her child with confidence | 16 | 8% |
| Firm with her child | 1 | .3% |
| Total | 181 | 96.4% |
| Negative Interactions with child | | |
| Rough with her child | 3 | 2% |
| Impatient | 1 | .3% |
| In a hurry with her child | 2 | 1% |
| Seemed to resent her child | 1 | .3% |
| Total | 7 | 3.6% |
| Grand Total | 188 | 100% |

5.2.4. How the Mother has been affected by having a Disabled Child.

In Table 5.2.4.A. 34 (71%) mothers described how sad and unhappy they had felt when they first realized their child had a problem. One mother described how she had started to worry, as she knew that she now carried an extra burden that would last for as long as the child lived. She felt the child would never be ordinary and happy and play easily with other children. To quote another mother:

I was very upset, but had to pull myself together as I have to look after the child.

A couple of mothers described in a matter of fact way how they had to accept the problem and then get on with looking after the child. They seemed to imply that the feelings they had were insignificant as there was no place or time for them. One mother in an accepting response said:

I was not sad, I just thank God she was alive.

TABLE 5.2.4.A. THE MOTHERS FEELINGS WHEN SHE FIRST REALIZED THAT HER CHILD HAD A PROBLEM

| Mother's feelings | Frequency | Percentage |
|------------------------------|-----------|------------|
| Very sad and unhappy | 34 | 71% |
| Cried | 5 | 11% |
| So upset she became ill | 2 | 4% |
| Denied at first and then sad | 2 | 4% |
| Accepted it | 2 | 4% |
| Blamed myself | 2 | 4% |
| Worried | 1 | 2% |
| Total | 48 | 100% |

TABLE 5.2.4.B THE MOTHERS PRESENT FEELINGS ABOUT HER CHILD.

| Mother's responses | Frequency | Percentage |
|--------------------------------|-----------|------------|
| Positive Feelings | 24 | 50% |
| Happy | 13 | 27% |
| Still have hope | 9 | 19% |
| Better because he is better | 2 | 4% |
| Feelings of Reservation | 19 | 40% |
| Not so sad anymore | 7 | 15% |
| Resigned | 6 | 13% |
| OK now | 6 | 12% |
| Feelings of Anxiety | 5 | 10% |
| Still sad and worried | 5 | 10% |
| Total | 48 | 100% |

In Table 5.2.4.B. the responses of the mothers fell into three groups. The first group of 24 mothers (50%), had positive feelings about their child now:

I am happy now because he is alive and God gave me the child and I love him.

19 (40%) mothers responded with more reservation saying that they felt better now than they had at first, but still did not feel positive about their children. 5 (10%) mothers expressed that they still felt very sad and worried about their child.

In Section 5.3.17. once the outcome indicators have been analyzed, the feelings and hopes of the mothers will be analyzed to determine to what extent these influence the outcome indicators.

TABLE 5.2.4.C. MOTHER'S RESPONSES TO THE QUESTION
" WHAT HAS HELPED YOU MANAGE WITH YOUR DISABLED CHILD?"

| Mother's responses | Frequency | Percentage |
|------------------------------------|-----------|------------|
| RWs | 22 | 46% |
| God | 6 | 12% |
| Other mothers of disabled children | 7 | 15% |
| Hospital | 3 | 6% |
| The support of the father | 4 | 8% |
| Nothing has helped | 6 | 13% |
| Total | 48 | 100% |

From Table 5.2.4.C. it can be seen that 22 (46%) mothers said that the advice and/or exercises of the RWs had helped them.

It is the RW who is always with me and advises me.

It is the RWs by visiting me and giving me advice every time I realize I am not staying alone.

A number of other people who had helped them were mentioned by different mothers. 6 (13%) mothers said that nothing has helped them.

I have been everywhere trying to get help.

5.2.5. Maternal Attitude to the Rehabilitation Workers.

Only 2 (4%) mothers were not able to name the RW. 32 (67%) of the mothers knew that the RWs worked for SACLA. In Table 5.2.5.A. it can be seen that 26 (55%) mothers said that the reason the RW comes to visit her is to see the child. 16 (33%) mothers said that the RW comes to visit to help the mother. Comments were as follows:

She visits me because of my disabled child, she knows about these children because she has a disabled child of her own.

She advises me and takes care of me.

| TABLE 5.2.5.A. REASON FOR THE VISIT OF THE RWS | | |
|--|-----------|------------|
| Reason for visit | Frequency | Percentage |
| She cares for my child | 26 | 55% |
| She comes to support me | 16 | 33% |
| To care for both my child and me | 3 | 6% |
| I am unable to go to hospital | 3 | 6% |
| Total | 48 | 100% |

No mothers expressed negative feelings about the RWS visits. 47 (98%) mothers said they felt much happier after the RWS visits. The only mother who did not respond in this way, expressed that she feels no happier after the RWS visit, as her child is not getting better. The quotes below indicate the extent of the mother's feelings.

Sometimes I feel like she cannot go.

I feel happy and have rest in my soul.

I feel happy because she helps me with everything.

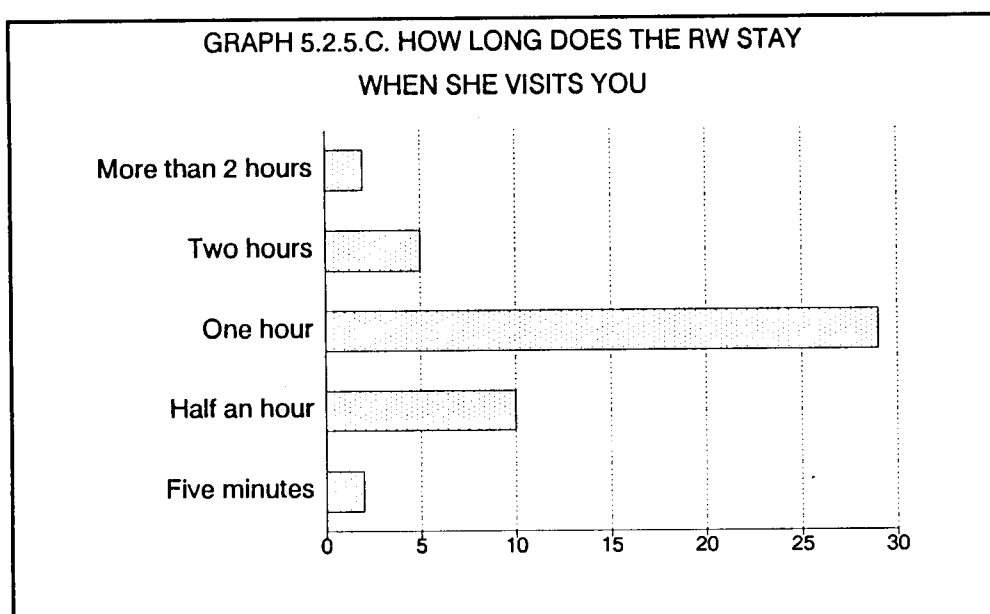
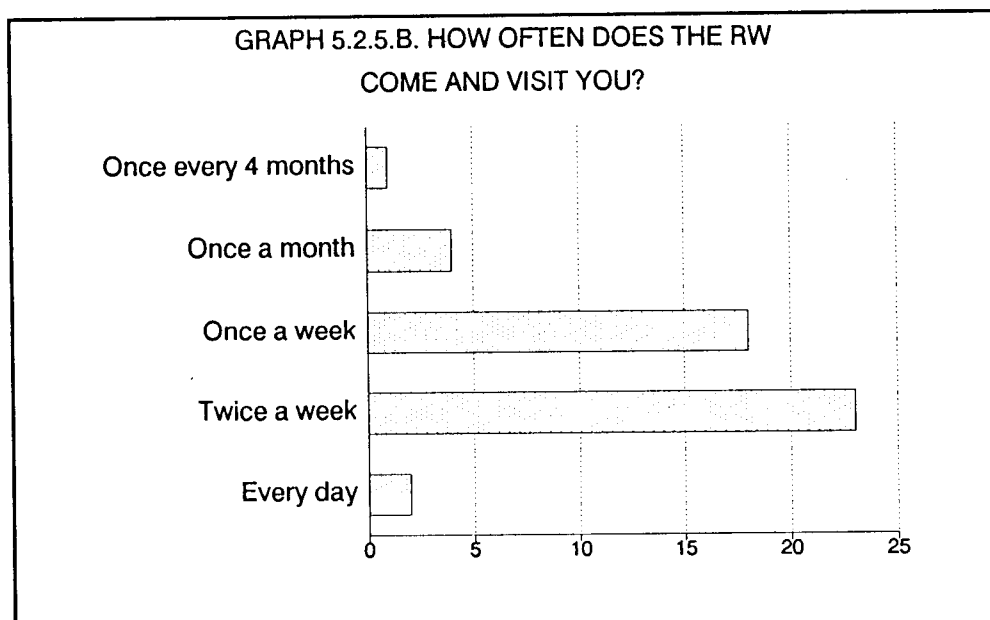
She talks nicely to me and takes her time with my child.

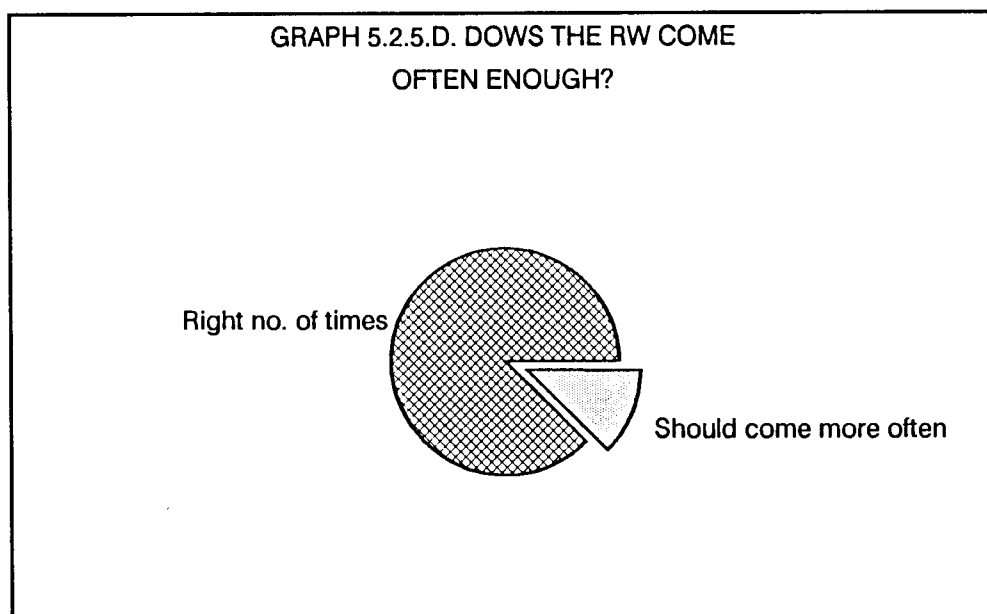
I feel happy, because if I have a problem it stops.

Every time she comes I feel happy and I want her to stay with me.

43 (90%) of the mothers said that the RW visits them at least once a week (Graph 5.2.5.B.). 36 (73%) of the mothers said that the RW stays at least an hour when she visits them (Graph 5.2.5.C.). 42 (88%) of the mothers expressed satisfaction with the number of times that the RW visits them (Graph 5.2.5.D.). One mother said:

When I don't see her I think maybe she doesn't care for my child.





In Table 5.2.5.E. it can be seen that 23 (48%) mothers spoke to the RWs about their problems. Two mothers said:

I don't speak to the RW about my problems as she didn't ask me about my problems.

It is good to speak to the RW, but it makes me very sad. I thought my child was the only disabled child. Now I know there are many other children who also have problems.

In section 5.3.18. once the performance indicators have been analyzed the frequency and duration of the RWs visits will be analyzed to determine what effect they had on the performance indicators.

TABLE 5.2.5.E. DO YOU TALK TO THE RW ABOUT YOUR FEELINGS FOR YOUR CHILD?

| Mother's Responses | No. of Mothers | % |
|--|----------------|------|
| Spoke to her, wanted her advice and help | 23 | 48% |
| Don't speak, don't know what to say | 16 | 34% |
| Did not respond | 7 | 14% |
| Don't speak, don't think she can help me | 1 | 2% |
| I have no problems and no thoughts | 1 | 2% |
| Total | 48 | 100% |

In response to whether the mothers perceive their child to be better, 23 (48%) mothers answered that their children had improved a lot (Table 5.2.5.F.). Two mothers responded in the following way:

The child is better, he can concentrate better now and think better.

My child is better, he is now able to play with children the same age.

| TABLE 5.2.5.F. PROGRESS OF YOUR CHILD | | |
|---------------------------------------|-----------|------------|
| Mothers answers | Frequency | Percentage |
| Improved a lot | 23 | 48% |
| Improved a little | 13 | 27% |
| Stayed the same | 3 | 6% |
| Some ways better, others no better | 5 | 11% |
| Some ways better, others worse | 4 | 8% |
| Total | 48 | 100% |

When asked why they felt the child had progressed 25 (53%) mothers said that their child had improved functionally (Table 5.2.5.G.). 1 (2%) mother said she had been away and had not seen the RW so that her child is more stiff now.

| TABLE 5.2.5.G. INDICATIONS OF PROGRESS | | |
|---|-----------|------------|
| Mothers Responses | Frequency | Percentage |
| Can do things now unable to do before | 25 | 53% |
| Not as stiff anymore | 8 | 17% |
| Still the same | 6 | 12% |
| Some parts better, others no better | 5 | 10% |
| Child is better after exercises | 2 | 4% |
| I have been away, so the child is stiff | 1 | 2% |
| Did not answer this question | 1 | 2% |
| Total | 48 | 100% |

5.2.6. Maternal Perception of the Importance of the Exercises.

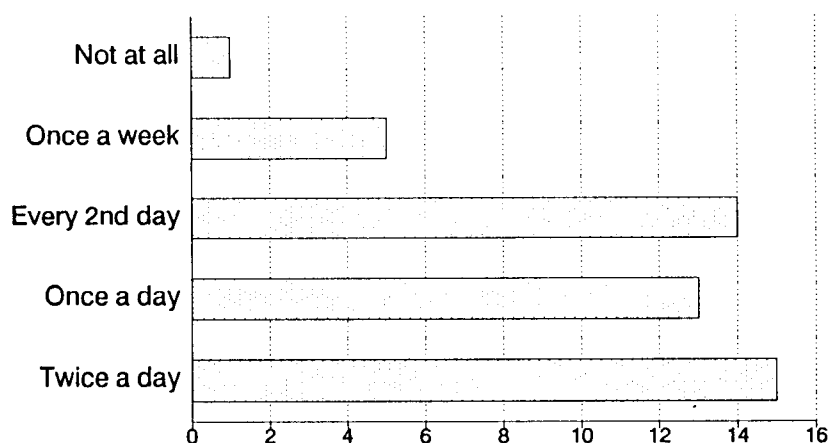
All the mothers stated that they felt the exercises were important. When asked "What do you think the exercises have done for your child?" 45 (94%) of the mothers said that the exercises helped their child and 3 (6%) said they made little difference. None of the mothers answered that they had harmed their child (Table 5.2.6.A.).

28 (58%) mothers answered that they did the exercises at least once a day (Graph 5.2.5.B.).

TABLE 5.2.6.A. MATERNAL PERCEPTION AS TO WHETHER THE EXERCISES HELP, MAKE LITTLE DIFFERENCE, OR HARM THE CHILD.

| | No. of Mothers |
|---|----------------|
| Did the exercises help? | 45 |
| Did the exercises make little difference? | 3 |
| Did the exercises harm her? | 0 |
| Total | 48 |

GRAPH 5.2.6.B. MATERNAL RESPONSES INDICATING FREQUENCY OF EXERCISES



5.3. THE PERFORMANCE OF THE CAREGIVERS.

UNIVARIATE ANALYSIS

5.3.1. Performance of Exercises by the Caregiver.

Table 5.3.1. shows how the caregivers performed their exercises when the performance averages are grouped together to the nearest 0.5.

| TABLE 5.3.1. FREQUENCY OF AVERAGE PERFORMANCE SCORE (A.P.S.). | | |
|---|-----------|---------|
| A.P.S. | Frequency | Percent |
| 2.0 | 1 | 2% |
| 2.5 | 1 | 2% |
| 3.0 | 1 | 2% |
| 3.5 | 7 | 15% |
| 4.0 | 14 | 29% |
| 4.5 | 12 | 25% |
| 5.0 | 12 | 25% |
| Median = 4.25 | Total 48 | 100% |

38 (79%) of the caregivers achieved 4.0 or above as a performance average for the exercises they showed the therapists.

Only 3 (6%) caregivers scored between 2.0 and 3.0. All three of these caregivers (who were mothers) had a good reason for not scoring well, which is unrelated to the project. The mother who scored 2.0 was totally preoccupied at the time with a domestic problem at home and said to the therapist "I cannot remember any exercises at the moment, because of the problems in my house." The mother who scored 2.5 had not being seen regularly by the RW at the time of the evaluation as her child was at a day care centre in a neighbouring township each day of the week. The RW treated the child there and had not seen the mother for some time. The mother who scored 3.0 did two exercises which were not taught by the SACLA rehabilitation team.

She obtained a low score as these exercises were not well done. The greater concern is the 7 (15%) of caregivers who scored 3.5.

A total of 155 exercises were performed by the 48 caregivers, and the aggregate score was 665. The median of the caregivers's A.P.S. was 4.25.

5.3.2. Exercises Remembered by the Caregivers.

This outcome indicator concerns the number of exercises the caregiver is supposed to do with the child, but forgot to perform. 28 (59%) of the caregivers remembered all the exercises they were taught. 6 (12%) caregivers forgot more than one exercise (Table 5.3.2.).

| TABLE 5.3.2.: NUMBER OF EXERCISES REMEMBERED BY THE CAREGIVERS. | | |
|---|------------|--------------------------------|
| No. of Caregivers | Percentage | Number of Exercises Remembered |
| 28 | 59% | All |
| 14 | 29% | 1 forgotten |
| 3 | 6% | 2 forgotten |
| 3 | 6% | 4 forgotten |
| Total 48 | 100% | Median = 0 |

5.3.3. Level of Socialization between the Caregiver and Child.

From Table 5.3.3. it can be seen that 40 (83%) mothers interacted adequately with their child so stimulating the development of socialization.

TABLE 5.3.3. LEVEL OF SOCIALIZATION BETWEEN CAREGIVER AND CHILD

| Level of Interaction | Number of Caregivers | Percentage |
|-----------------------------------|----------------------|-------------|
| Adequate Interaction | 40 | 83% |
| Verbal interaction | 35 | 73% |
| Verbal and non-verbal interaction | 5 | 10% |
| Inadequate Interaction | 8 | 17% |
| No interaction at all | 6 | 13% |
| Minimal interaction | 2 | 4% |
| Total | 48 | 100% |

5.3.4. Extent of Language Development.

29 (60%) caregivers did not stimulate the child in an attempt to develop their language. 19 (40%) caregivers attempted to include language development in different ways which were all satisfactory, these included making sounds, imitating, naming body parts, counting, talking and singing.

5.3.5. Development of Self Help Skills.

Table 5.3.5. shows that 20 (42%) caregivers did nothing with regard to the development of self help skills. The remaining 28 (58%) caregivers were involved in teaching their children a number of different skills besides those mentioned in the table. These included toilet and mobility training.

TABLE 5.3.5. DEVELOPMENT OF SELF HELP SKILLS

| Level of interaction | No. of Caregivers | Percentage |
|--------------------------------------|-------------------|------------|
| Nothing with regard to self help | 20 | 42% |
| Feeding and drinking | 15 | 31% |
| Washing and dressing | 5 | 10% |
| Different activities of daily living | 3 | 6% |
| Child independent | 5 | 11% |
| Total | 48 | 100% |

5.3.6. Cognitive Development

As it can be seen from the Table 5.3.6. 13 (27%) caregivers either did nothing to stimulate cognitive development or needed to do more.

TABLE 5.3.6. COGNITIVE DEVELOPMENT

| Level of Interaction | No. of Caregivers | Percentage |
|-------------------------------|-------------------|------------|
| Adequate interaction | 35 | 73% |
| Holding a toy | 13 | 27% |
| Concentrating | 7 | 15% |
| Playing with beads, counting | 7 | 15% |
| Writing and drawing | 4 | 8% |
| Inadequate interaction | 13 | 27% |
| Nothing done | 6 | 12% |
| Done but needs more attention | 5 | 11% |
| Try new things | 1 | 2% |
| Done so badly, ineffective | 1 | 2% |
| Total | 48 | 100% |

5.3.7. Child Actively Involved in Treatment.

In Table 5.3.7.A. it can be seen that 37 (77%) caregivers actively involved the child in the development of fine motor skills. In table 5.3.7.B. it can be seen that 40 (83%) caregivers involved the child actively in the development of gross motor skills.

TABLE 5.3.7.A. FINE MOTOR DEVELOPMENT

| Level of Interaction | No. of Caregivers | Percentage |
|-------------------------------|-------------------|-------------|
| Adequate involvement | 37 | 77% |
| Caregiver with child involved | 28 | 58% |
| Child active | 9 | 19% |
| Inadequate involvement | 11 | 33% |
| Not done | 9 | 19% |
| Child passive | 2 | 4% |
| Total | 48 | 100% |

TABLE 5.3.7.B. GROSS MOTOR DEVELOPMENT.

| Level of interaction | No.of Caregivers | Percentage |
|-------------------------------|------------------|-------------|
| Adequate involvement | 40 | 83% |
| Child active | 30 | 62% |
| Caregiver with child involved | 10 | 21% |
| Inadequate involvement | 8 | 17% |
| Child passive | 6 | 13% |
| Not done | 2 | 4% |
| Total | 48 | 100% |

5.3.8. Prioritizing Exercises.

From Table 5.3.8. it can be seen that 16 (33%) of the caregivers were able to prioritize both activities. The 8 (17%) caregivers who were not able to prioritize included 4 (8%) cases where no activities were demonstrated as three children were sleeping and the caregivers did not want to wake them up, and one child who was not there at the time of the interview.

TABLE 5.3.8. FREQUENCY OF PRIORITY SCORES

| No. of exercises Prioritized | No.of Caregivers | Percentage |
|---------------------------------|------------------|------------|
| 0 | 8 | 17% |
| 1 | 24 | 50% |
| 2 | 16 | 33% |
| Median = 1 | Total 48 | 100% |

5.3.9. Progression of Exercises.

28 (58%) of the caregivers progressed the exercises whereas 20 (42%) did not progress the exercises.

5.3.10. Positions Used for Exercises.

As can be seen from Table 5.3.10 exercises taught by the SACLA therapists and RWs were performed in a number of different positions. Sitting (not side sitting) was the most common position used followed by standing.

TABLE 5.3.10. POSITIONS USED FOR EXERCISES TAUGHT BY SACLA.

| Position | No. of Exercises | Percentage |
|-------------------------|------------------|------------|
| Lying | 48 | 31% |
| Supine lying | 13 | 8% |
| Side lying | 17 | 11% |
| Prone lying | 18 | 12% |
| Sitting | 60 | 39% |
| Sitting | 51 | 33% |
| Side sitting | 9 | 6% |
| Becoming upright | 47 | 30% |
| Kneeling | 9 | 6% |
| Standing | 30 | 19% |
| Walking | 8 | 5% |
| Total | 155 | 100% |

BIVARIATE ANALYSES

5.3.11 Bivariate Analyses of Average Performance Score (A.P.S.) and a Number of Different Exposure Variables.

Table 5.3.11. shows that the caregiver's A.P.S. was significantly affected by the child's age (the A.P.S. was highest with the oldest category of children, however there was no age trend), the identity of the caregiver (mother's performance was the poorest) and maternal age (mature and young mothers performed poorly).

TABLE 5.3.11.: AVERAGE PERFORMANCE SCORE (A.P.S.) OF CAREGIVER AND A NUMBER OF DIFFERENT EXPOSURE VARIABLES.

| FACTORS | NUMBER IN EACH CATEGORY | % OF CGS* WHO SCORED HIGH (>4.25) | CHI TEST INDICATING SIGNIFICANCE |
|---|-------------------------------|---|--|
| <u>1. Age of child.</u> | | | |
| 1 - 2 | 15 | 47 | p = 0.00927 Significant |
| 3 - 5 | 17 | 41 | |
| 6 - 12 years | 16 | 62 | |
| <u>2. Status of child.</u> | | | |
| Old | 38 | 50 | p = 1 Not signif. |
| New | 10 | 50 | |
| <u>3. Prime caregiver.</u> | | | |
| Mother | 40 | 48 | p = 0.03282 Significant |
| Not mother | 8 | 63 | |
| <u>4. Age of mother, where she is primary care-giver.</u> | | | |
| 15 - 24 | 16 | 44 | p = 0.02621 Significant |
| 25 - 34 | 10 | 60 | |
| 35 - 50 years | 14 | 43 | |
| <u>5. Father present in home.</u> | | | |
| Present | 31 | 48 | p = 0.4794 Not signif. |
| Not-present | 17 | 53 | |
| <u>6. Number of people in home.</u> | | | |
| 1 - 6 | 26 | 50 | p = 1 Not signif. |
| 7 - 12 people | 22 | 50 | |

* CGS = caregivers

5.3.12.: Bivariate Analyses of Exercises Remembered and a Number of Different Exposure Variables.

Table 5.3.12.A. shows that the number of exercises remembered by the caregiver was significantly affected by the age of the child, (fewer caregivers of children between 3 and 5 years of age remembered all the exercises than caregivers of younger and older children, there was no age trend), the identity of the caregiver (fewer mothers remembered all the exercises) and maternal age (there was a trend for age, with fewer younger mothers remembering all the exercises).

TABLE 5.3.12.A.: EXERCISES REMEMBERED AND A NUMBER OF DIFFERENT EXPOSURE VARIABLES

| <u>FACTORS</u> | NUMBER IN EACH CATEGORY | % OF CGS* WHO REMEMBERED ALL EXERCISES | CHI TEST INDICATING SIGNIFICANCE |
|---|-------------------------------|--|--|
| <u>1. Age of child.</u> | | | |
| 1 - 2 | 15 | 67 | p = 0.00004 |
| 3 - 5 | 17 | 41 | Significant |
| 6 - 12 years | 16 | 69 | |
| <u>2. Status of child.</u> | | | |
| Old | 38 | 61 | p = 0.117 |
| New | 10 | 50 | Not signif. |
| <u>3. Prime caregiver.</u> | | | |
| Mother | 40 | 55 | p = 0.00302 |
| Not mother | 8 | 75 | Significant |
| <u>4. Age of mother, where she is primary care-giver.</u> | | | |
| 15 - 24 | 16 | 44 | p = 0.00015 |
| 25 - 34 | 10 | 50 | Significant |
| 35 - 50 years | 14 | 72 | |
| <u>5. Father present in home.</u> | | | |
| Present | 31 | 58 | p = 0.885 |
| Not-present | 17 | 59 | Not signif. |
| <u>6. Number of people in home.</u> | | | |
| 1 - 6 | 26 | 54 | p = 0.15 |
| 7 - 12 people | 22 | 64 | Not signif. |

* CGS = caregivers

Bivariate Analyses Comparing Number of Exercises Remembered and Performance Group.

In Table 5.3.12.B. it can be seen that 34 (71%) caregivers scored both above 3.5 and remembered all or forgot only one exercise.

TABLE 5.3.12.B.: NUMBER OF EXERCISES REMEMBERED AND PERFORMANCE GROUP.

| | | Number of Exercises Remembered | | | | | |
|-------------------|-----|--------------------------------|--------|--------|--------|--------|-------|
| | | All | Forgot | Forgot | Forgot | Forgot | Total |
| | | | 1 | 2 | 3 | 4 | |
| Performance Group | 2.0 | 0 | 0 | 0 | 0 | 1 | 1 |
| | 2.5 | 0 | 1 | 0 | 0 | 0 | 1 |
| | 3.0 | 1 | 0 | 0 | 0 | 0 | 1 |
| | 3.5 | 3 | 3 | 1 | 0 | 0 | 7 |
| | 4.0 | 6 | 5 | 1 | 0 | 2 | 14 |
| | 4.5 | 8 | 4 | 0 | 0 | 0 | 12 |
| | 5.0 | 10 | 1 | 1 | 0 | 0 | 12 |
| Total | | 28 | 14 | 3 | 0 | 3 | 48 |

5.3.13. Bivariate Analyses of Socialization and a Number of Exposure Variables.

Table 5.3.13. shows that the age of the mother was the only factor which significantly affected the level of socialization. Younger mothers (15-24) showed poorer integration of socialization than older mothers. There was no age trend.

TABLE 5.3.13.: SOCIALIZATION AND A NUMBER OF EXPOSURE VARIABLES.

| <u>FACTORS</u> | NUMBER IN EACH CATEGORY | % OF CGS* WITH GOOD SOCIALIZATION | CHI TEST INDICATING SIGNIFICANCE |
|---|-------------------------------|---|--|
| <u>1. Age of child.</u> | | | |
| 1 - 2 | 15 | 80 | p = 0.260 |
| 3 - 5 | 17 | 88 | Not signif. |
| 6 - 12 years | 16 | 81 | |
| <u>2. Status of child.</u> | | | |
| Old | 38 | 84 | p = 0.46 |
| New | 10 | 80 | Not signif. |
| <u>3. Prime caregiver.</u> | | | |
| Mother | 40 | 80 | p = 0.0000 |
| Not mother | 8 | 100 | Significant |
| <u>4. Age of mother, where she is primary care-giver.</u> | | | |
| 15 - 24 | 16 | 62 | p = 0.000 |
| 25 - 34 | 10 | 90 | Significant |
| 35 - 50 years | 14 | 93 | |
| <u>5. Father present in home.</u> | | | |
| Present | 31 | 85 | p = 0.108 |
| Not-present | 17 | 76 | Not signif. |
| <u>6. Number of people in home.</u> | | | |
| 1 - 6 | 26 | 81 | p = 0.340 |
| 7 - 12 people | 22 | 86 | Not signif. |

*CGS = caregivers

5.3.14. Bivariate Analyses of Language Development and a Number of Different Exposure Variables.

Table 5.3.14. shows that the age of the mother and the presence of the father were the only two factors which significantly influenced language development. There was a trend in the age of the mother in that the older the mother the greater the involvement of language development.

TABLE 5.3.14.: LANGUAGE DEVELOPMENT AND A NUMBER OF DIFFERENT EXPOSURE VARIABLES.

| <u>FACTORS</u> | NUMBER IN EACH CATEGORY | % OF CGS* WHO INCLUDED LANGUAGE DEV. SATISFACTORILY | CHI TEST INDICATING SIGNIFICANCE |
|---|-------------------------------|--|--|
| <u>1. Age of child.</u> | | | |
| 1 - 2 | 15 | 33 | p = 0.13369 |
| 3 - 5 | 17 | 47 | Not Signif. |
| 6 - 12 years | 16 | 38 | |
| <u>2. Status of child.</u> | | | |
| Old | 38 | 39 | p = 0.884 |
| New | 10 | 40 | Not signif. |
| <u>3. Prime caregiver.</u> | | | |
| Mother | 40 | 40 | p = 0.662 |
| Not mother | 8 | 37 | Not signif. |
| <u>4. Age of mother, where she is primary care-giver.</u> | | | |
| 15 - 24 | 16 | 31 | p = 0.0243 |
| 25 - 34 | 10 | 40 | Significant |
| 35 - 50 years | 14 | 50 | |
| <u>5. Father present in home.</u> | | | |
| Present | 31 | 45 | p = 0.0191 |
| Not-present | 17 | 29 | Significant |
| <u>6. Number of people in home.</u> | | | |
| 1 - 6 | 26 | 35 | p = 0.14 |
| 7 - 12 people | 22 | 45 | Not signif. |

*CGS = caregivers

5.3.15. Bivariate Analyses of the Caregiver's Ability to Prioritize the Exercises and a Number of Different Exposure Variables.

Table 5.3.15. shows that the caregiver's ability to prioritize the exercises was significantly associated with the child's age (a trend is apparent here, the younger the child the easier it was for the caregiver to prioritize), the type of caregiver (mothers were less able to prioritize), and maternal age (mothers between 25 and 34 were less able to prioritize than older and younger mothers).

TABLE 5.3.15.: THE CAREGIVER'S ABILITY TO PRIORITIZE AND A NUMBER OF DIFFERENT EXPOSURE VARIABLES.

| NUMBER IN EACH CATEGORY | % OF CGS* WHO COULD PRIORITIZE | CHI TEST INDICATING SIGNIFICANCE |
|---|--------------------------------------|--|
| <u>1. Age of child.</u> | | |
| 1 - 2 15 | 47 | p = 0.00014 Signif. |
| 3 - 5 17 | 35 | |
| 6 - 12 years 16 | 19 | |
| <u>2. Status of child.</u> | | |
| Old 38 | 32 | p = 0.238 Not signif. |
| New 10 | 40 | |
| <u>3. Prime caregiver.</u> | | |
| Mother 40 | 30 | p = 0.003 Signif. |
| Not mother 8 | 50 | |
| <u>4. Age of mother, where she is primary care-giver.</u> | | |
| 15 - 24 16 | 31 | p = 0.0386 Significant |
| 25 - 34 10 | 20 | |
| 35 - 50 years 14 | 36 | |
| <u>5. Father present in home.</u> | | |
| Present 31 | 29 | p = 0.075 Not Signif. |
| Not-present 17 | 41 | |
| <u>6. Number of people in home.</u> | | |
| 1 - 6 26 | 31 | p = 0.423 Not signif. |
| 7 - 12 people 22 | 36 | |

*CGS = caregivers

5.3.16. Summary of Bivariate Analyses (Table 5.3.16.).

Maternal Age: For three outcome variables related to the mother's performance (exercises remembered, the level of socialization, and language development) there was an age trend with older mothers performing best. For one additional outcome variable the older mothers performed best, but there was no age trend (prioritizing exercises). For one outcome variable the older mothers scored least well. There was no age trend.

Prime Caregiver: The mothers performed less well for four of the outcome variables (average performance score, exercises remembered, the level of socialization and prioritizing exercises).

Age of Child: For two outcome variables (average performance score and exercises remembered) the caregivers of the older children 6-12 years old scored the best and the caregivers of the children 3-5 years old scored least well. For one outcome variable there was an age trend (prioritizing exercises) in that the older the child, the less well the mother performed.

Presence of the Father: Language development was the only variable in which the presence of the father was significant.

Number of People in the House: This did not significantly affect any of the outcome variables.

Status of the Child: This did not significantly affect any of the outcome variables.

Thus it can be seen that three exposure variables affected the outcome variables, these were the age of the child, the identity of the caregiver and the age of the mother if she was the caregiver.

TABLE 5.3.16.: SUMMARY OF OUTCOME VARIABLES AND EXPOSURE VARIABLES.

| OUTCOME VARIA- BLES | ----- EXPOSURE VARIABLES ----- | | | | | |
|--------------------------------------|---|-----------------------|----------------------------|---|--|--------------------------------|
| | Age of child | Status of child | Prime care giver | Age of mother | pres- ence of father | no. of people in home |
| Average Perfor- mance Score | 6-12 best 3-5 worst no age trend | n/s* | mothers scored worst | 35-50 worst 25-34 best no age trend | n/s | n/s |
| Exer- cises remem- bered | 6-12 best 3-5 worst | n/s | mothers scored worst | 15-24 worst 35-50 best age trend: older = better score | n/s | n/s |
| Level of social- isation | n/s | n/s | mothers scored worst | age trend: older = better score. | n/s | n/s |
| lang- uage devel- opment | n/s | n/s | n/s | age trend: older =the better the score | If father present did better | n/s |
| priori- tizing exer- cises | age trend: older = worse score | n/s | mothers scored worst | 25-34 worst 35-45 best no age trend | n/s | n/s |

Significant if $p > 0.05$.

* n/s = determined to be not significant by the chi squared test.

5.3.17. The Effects of Maternal Hopes and Feelings on the Different Outcome Variables.

From Table 5.3.17.A. it can be seen that mothers who expressed that they had little or no hope that their child would get better

performed significantly better in three of the outcome variables. They remembered exercises, included socialization and prioritized significantly better than mothers who expressed they had hope for their child. On the other hand the mothers who were hopeful included language stimulation significantly more than the other mothers.

With regard to maternal feelings about their child (Table 5.3.17.B.) two outcome variables were affected significantly. Mothers who expressed that they still felt sad about their child interacted significantly more with their child (socialization) and remembered the exercises significantly better.

TABLE 5.3.17.A. SUMMARY OF THE EFFECT OF MATERNAL HOPES ON OUTCOME VARIABLES.

(Note: These results only consider the 40 mothers who are the caregiver)

| | Hopeful | Not hopeful | Chi squared test. | Significant |
|---|---------|-------------|-------------------|-------------|
| <u>Number</u> | 29 | 11 | | |
| Performed <u>High >4.25</u> | 48% | 45% | p=0.6706 | Not sig. |
| Remembered <u>all exercises</u> | 38% | 100% | p=0.0000 | Sig. |
| Good <u>Socialization</u> | 76% | 91% | p=0.0042 | Sig. |
| Included <u>Language</u> | 48% | 26% | p=0.0015 | Sig. |
| Could Prioritize <u>Exercises</u> | 24% | 45% | p=0.0017 | Sig. |

TABLE 5.3.17.B. SUMMARY OF THE EFFECT OF MATERNAL FEELINGS ABOUT THEIR DISABLED CHILD ON OUTCOME VARIABLES.

(Note: These results only consider the 40 mothers who are the caregiver)

| | Happy | Sad | Chi squared test. | Significant |
|---|-------|------|-------------------|-------------|
| <u>Number</u> | 31 | 9 | | |
| Performed <u>High >4.25</u> | 48% | 44% | p=0.5703 | Not sig. |
| Remembered <u>all exercises</u> | 52% | 67% | p=0.0307 | Sig. |
| Good <u>Socialization</u> | 74% | 100% | p=0.0000 | Sig. |
| Included <u>Language</u> | 42% | 44% | p=0.775 | Not sig. |
| Could Prioritize <u>Exercises</u> | 32% | 22% | p=0.1112 | Not sig. |

5.3.18. The Effect of Frequency and Duration of the RWs Visits on the Different Outcome Indicators.

From Table 5.3.18.A. it can be seen that the frequency with which RWs visit children effects three outcome variables significantly.

Mothers who were visited less than twice a week performed significantly better in the following three outcome variables: remembering exercises, extent of social interaction with their child and language stimulation.

From Table 5.3.18.B. it can be seen that mothers who were visited by the RWs for longer than an hour performed significantly better for three of the outcome variables. They performed exercises better, remembered more exercises and were able to prioritize the exercises.

TABLE 5.3.18.A. SUMMARY OF THE EFFECT OF THE FREQUENCY OF RWS VISIT ON THE OUTCOME VARIABLES.

(Note: These results only consider the 40 mothers who are the caregiver)

| | 2x a week | Less than 2x a week | Chi squared test. | Significant |
|---|-----------|---------------------|-------------------|-------------|
| <u>Number</u> | 21 | 19 | | |
| Performed <u>High >4.25</u> | 52% | 42% | p=0.1565 | Not sig. |
| Remembered <u>all exercises</u> | 48% | 63% | p=0.0328 | Sig. |
| Good <u>Socialization</u> | 72% | 95% | p=0.0000 | Sig. |
| Included <u>Language</u> | 33% | 53% | p=0.0042 | Sig. |
| Could Prioritize <u>Exercises</u> | 33% | 26% | p=0.2777 | Not sig. |

TABLE 5.3.18.B. SUMMARY OF THE EFFECT OF THE DURATION OF RWS VISIT ON THE OUTCOME VARIABLES.

(Note: These results only consider the 40 mothers who are the caregiver)

| | Less than 1 hour | 1 hour or more | Chi squared test. | Significant |
|---|------------------|----------------|-------------------|-------------|
| <u>Number</u> | 9 | 31 | | |
| Performed <u>High >4.25</u> | 33% | 52% | p=0.0065 | Sig. |
| Remembered <u>all exercises</u> | 44% | 58% | p=0.0476 | Sig. |
| Good <u>Socialization</u> | 78% | 81% | p=0.5992 | Not sig. |
| Included <u>Language</u> | 45% | 42% | p=0.6687 | Not sig. |
| Could Prioritize <u>Exercises</u> | 11% | 35% | p=0.0000 | Sig. |

5.4. RELATIONSHIP TO OTHER ORGANIZATIONS

5.4.1. Use of Other Services.

In response to the question "Since you started seeing the RW have you been to see anybody else or any other service to find help for your child?", 33 (69%) mothers had not taken their child to see anybody else or any other service (Table 5.4.1.).

| TABLE 5.4.1: USE OF OTHER SERVICES | | |
|------------------------------------|-----------|------------|
| Mother's Responses | Frequency | Percentage |
| Nowhere else | 33 | 69% |
| Witch doctor | 6 | 13% |
| Day hospital | 3 | 6% |
| Social worker | 3 | 6% |
| Hospital | 3 | 6% |
| Total | 48 | 100% |

5.4.2. RW Service Compared to the Other Services.

In this section the service offered by the SACLA RWS is compared to that offered by the physiotherapists (PTs) at one of Cape Town's tertiary hospitals.

TABLE 5.4.2.A.: MOTHER'S RESPONSES TO THE QUESTION
"HOW DO YOU FEEL THE RWS HANDLE YOUR CHILD COMPARED
TO THE PHYSIOTHERAPISTS AT THE HOSPITAL?"

| Mothers responses | Frequency | Percentage |
|------------------------------------|-----------|------------|
| RW handles the child nicely | 19 | 40% |
| They handle the child the same | 14 | 29% |
| RW doesn't have the same equipment | 2 | 4% |
| Prefer RW for different reasons | 6 | 12% |
| Have not been to PTs at hospital | 7 | 15% |
| Total | 48 | 100% |

From Table 5.4.2.A. it can be seen that 19 (40%) of the mothers said that the RW handled their child nicely. Some of the reasons for the mother saying she preferred the RW are included below:

At the hospital they just look at him and tell me to take him to SACLA.

It is better to go to the RW than to the hospital, because to go to the hospital you have to pay money for transport.

The RW works with my child, at the hospital they work with a doll.

TABLE 5.4.2.B.: MOTHER'S RESPONSES TO THE QUESTION
"HOW DO YOU FEEL THE RW TALKS TO YOU COMPARED TO
THE PHYSIOTHERAPISTS AT THE HOSPITAL?"

| Mothers responses | Frequency | Percentage |
|----------------------------------|-----------|------------|
| RW speaks clearly,.... | 28 | 58% |
| They talk the same | 13 | 27% |
| Have not been to PTs at hospital | 7 | 15% |
| Total | 48 | 100% |

Table 5.4.2.B. shows that 33 (70%) of the mothers said that they liked the way the RW spoke to them, many of them mentioning common language as positive factor. 7 (15%) are excluded as they had not

been seen by the physiotherapists at the hospital. The category "RW speaks...." in Table 5.4.2.B. was usually expressed as:

The RW speaks clearly, I understand as she speaks in my own language, this makes a big difference.

The RW is the best person because she comes again and again and she is also in my community.

5.4.3. Who Else has Taught the Mother's Exercises?

45 (94%) mothers said they had been taught exercises by the RW (Table 5.4.3.). 16 (33%) mothers said they were confused about which exercises they should do. All of the mothers who reported being taught exercises at the tertiary hospital said they were confused.

TABLE 5.4.3.: MOTHER'S RESPONSES TO THE QUESTION
"HAS ANYBODY ELSE TAUGHT YOU EXERCISES?"

| Mothers responses | Frequency | Percentage |
|-----------------------------------|-----------|------------|
| No other exercises taught to me | 30 | 62% |
| Hospital | 8 | 17% |
| SACLA rehabilitation therapist | 7 | 15% |
| SACLA rehabilitation co-ordinator | 1 | 2% |
| Another RW | 2 | 4% |
| Total | 48 | 100% |

5.4.4. Maternal Perception as to How the RW has Been of Assistance.

Some of the mothers named other ways in which the RWs had helped them.

The RW referred my child to a support group.
Because of the RW my child gets a Christmas present each Christmas.

She taught me how to play with my child.

Table 5.4.4. shows that 19 (40%) mothers mentioned referral to other services, support and advice without being prompted, whereas only 16 (33%) mentioned exercises, although when prompted the remaining 32 (67%) remembered that exercises had been taught to them. 15 (31%) mothers said that the RWs had referred them to SHAWCO for milk powder for their child. 2 (4%) mothers mentioned how both the RW and the community health worker had helped her a lot.

| TABLE 5.4.4: MOTHER'S RESPONSES TO THE QUESTION "IN WHAT WAYS HAS THE RW HELPED YOU, IF ANY?" | | | | |
|--|------------|----------|-------|------|
| | Unprompted | Prompted | Total | % |
| Made appointments | 19 | 17 | 36 | 75% |
| Taught exercises | 16 | 32 | 48 | 100% |
| Gave advice | 18 | 17 | 35 | 73% |
| Gave support | 19 | 18 | 37 | 77% |

5.4.5. Exercises Added.

5.4.5.1. Exercises Added by the Mothers.

When the caregivers performed the exercises for the therapists they also performed a number of exercises (60) which were not taught to them by the SACLA rehabilitation therapists (Table 5.4.5.1.).

TABLE 5.4.5.1: NUMBER OF EXERCISES ADDED BY THE CAREGIVERS.

| Number of Caregivers | Number of Exercises Added | Total Number of Exercises |
|----------------------|---------------------------|---------------------------|
| 13 | 0 | |
| 18 | 1 | 18 |
| 12 | 2 | 24 |
| 3 | 3 | 9 |
| 1 | 4 | 4 |
| 1 | 5 | 5 |
| | Total 48 | 60 |

5.4.5.2. Comparing Taught and Added Exercises.

From Tables 5.4.5.2.A and B the scoring given for added and taught exercises can be seen. There was a total of 187 taught exercises. 32 were forgotten, so that 155 exercises were performed by the caregivers. No score was given for the 32 forgotten exercises so they are not included in the table below. It can be seen that the mean of the taught exercises (4.3) is higher than that of the added exercises (3.9).

TABLE 5.4.5.2.A: SCORING OF TAUGHT EXERCISES

| Number of Exercises (A) | Score (B) | Total Score (A x B) | Percentage |
|---------------------------------|-----------|---------------------|------------|
| 73 | 5 | 365 | 47% |
| 57 | 4 | 228 | 37% |
| 23 | 3 | 69 | 15% |
| 1 | 2 | 2 | 0.5% |
| 1 | 1 | 1 | 0.5% |
| Total 155 | | 665 | 100% |
| Mean score for taught exercises | | 4.3 | |

TABLE 5.4.5.2.B:.. SCORING OF ADDED EXERCISES

| Number of Exercises (A) | Score (B) | Total Score (A x B) | Percentage |
|--------------------------------|-----------|---------------------|------------|
| 20 | 5 | 100 | 33% |
| 22 | 4 | 88 | 37% |
| 11 | 3 | 33 | 18% |
| 6 | 2 | 12 | 10% |
| 1 | 1 | 1 | 2% |
| Total 60 | | 234 | 100% |
| Mean score for added exercises | | 3.9 | |

5.4.5.3. Different Sources from which the Added Exercises Came and How Well they were Performed.

TABLE 5.4.5.3.A: SOURCES OF ADDED EXERCISES

| Source | Number of Added Exercises |
|------------------------|---------------------------|
| Rehabilitation Workers | 17 |
| Hospital PTs | 19 |
| Old Exercises | 15 |
| Unknown | 9 |
| Total | 60 |

TABLE 5.4.5.3.B: SCORING FOR DIFFERENT SOURCES OF ADDED EXERCISES

| Different Sources | Scores 1 - 5 | | | | |
|---------------------------|--------------|---|----|----|----|
| | 1 | 2 | 3 | 4 | 5 |
| SACLA Therapists | 0 | 0 | 5 | 1 | 3 |
| Rehabilitation Workers | 0 | 1 | 1 | 6 | 8 |
| Hospital Physiotherapists | 1 | 4 | 1 | 9 | 5 |
| Old Exercises | 0 | 1 | 4 | 6 | 4 |
| Total | 1 | 6 | 11 | 22 | 20 |

From Table 5.4.5.3.B. it can be seen that only one exercise scored 1. This exercise was passive movements taught at the hospital. They were so badly done by the caregiver that the child screamed in pain

and her tone increased instead of decreasing. Old exercises refers exercises which were taught to the RWs and caregivers by the therapists but have been discontinued.

Some of the RWs are developing the confidence to take initiative themselves and teach mothers exercises which they think are appropriate. In 8 out of 10 cases (80%) this initiative was very positive. However, in one case the exercise was inappropriate and in the other case the exercise added by the RW exacerbated the condition of the child.

5.4.5.4 Bivariate Analyses Comparing the Scores of Added and Taught Exercises.

Bivariate analyses was done comparing the scores of the added and taught exercises. Exercises which scored 5 were compared (Table 5.4.5.4.).

TABLE 5.4.5.4.: EXERCISES TAUGHT BY SACLA COMPARED WITH EXERCISES ADDED FROM OTHER SOURCES

| Source | Number | % of exercises which scored 5 | Chi square test |
|------------------|--------|-------------------------------|----------------------------|
| SACLA Therapists | 155 | 47% | p = 0.00041 Significant |
| RW | 17 | 47% | |
| Hospital PTs | 19 | 26% | |
| Old exercises | 15 | 27% | |

The chi squared test showed that there is a significant difference between the scores obtained from the different sources. There is no difference in the performance of the exercises initiated by the SACLA therapists and those initiated by the RWs. However, exercises taught by the hospital physiotherapists and old exercises were performed

significantly worse than exercises taught by the SACLA therapists and the RWs.

5.5. ANALYSIS OF INDIVIDUAL RWS.

5.5.1. Analysis of Individual RWs with regard to Average Performance Scores of the Caregiver.

The number of exercises taught by each RW varied between 10 and 33. The percentage of exercises which scored five varied between 68% for RW number 6 and 20% for RW number 9. When the chi squared test was done ($p = 0.0000$) it indicated a significant difference between the performance of exercises taught by different RWs. This can be clearly noted in Table 5.5.1.

5.5.2. Analysis of Individual RWs with regard to the Number of Exercises Remembered by the Caregiver.

The number of caregivers evaluated for each RW varied between 3 and 8. The number of caregivers who remembered all the exercises varied between 80% for RW number 3 and 0% for RW number 9. When the chi squared test was done ($p = 0.00000$) it indicated a significant difference between the performance of caregivers seen by different RWs (Table 5.5.1.).

TABLE 5.5.1. ANALYSIS OF INDIVIDUAL RWS WITH REGARD TO PERFORMANCE AVERAGE SCORES OF THE CAREGIVER AND NUMBER OF EXERCISES REMEMBERED BY THE CAREGIVER.

| W | No. of CGS [*] Evaluated | % exercises scoring 5 | % CG who remembered all exercises |
|---|--------------------------------------|--------------------------|--------------------------------------|
| 1 | 7 | 32% | 57% |
| 2 | 4 | 57% | 75% |
| 3 | 5 | 50% | 80% |
| 4 | 6 | 41% | 50% |
| 5 | 8 | 21% | 75% |
| 6 | 7 | 68% | 57% |
| 7 | 3 | 58% | 67% |
| 8 | 5 | 23% | 40% |
| 9 | 3 | 20% | 0% |

* CGS = caregivers

CHAPTER SIX: DISCUSSION.

6.1. THE VALIDITY AND QUALITY OF THE DATA.

6.1.1. Sample Size.

The sample size for this evaluation was 48. This is a small number and thus it is questionable whether dogmatic claims can be made on the basis of the data, especially the factors identified through the bivariate analyses. Nevertheless, the sample size used was larger than all other evaluations of the home visiting programme of CBR projects available in the literature, and certain trends and concerns can be discerned. It should also be noted that to determine the reliability of some of the answers they were asked both in the major and minor questionnaire.

6.1.2. Daily Living Activities.

One of the aims of the questionnaire was to measure the extent to which daily living activities were performed by the caregiver and how well these are carried out. In both the major and minor questionnaires the interviewers and therapists were asked to observe the arrival activity of the child, hoping to find out if children were being placed in positions which would benefit them. However, the validity of this data is questionable as not enough detail was recorded to be able to tell in the analysis if the caregiver was carrying out daily living activities in a way which would benefit the child or not.

Very few daily living activities were demonstrated to the therapists. In asking the caregivers to demonstrate the activities they do with their child they may have assumed this excluded the routine activities of daily living and performed only more specific exercise like activities.

6.1.3. The Superficiality of Some Answers.

On analyzing the results it became apparent that some of the questions which required answers in more depth, were in fact answered superficially. The responses with regard to the problem with their child were too vague for any meaningful comparison to be made between the medical diagnosis of the child's condition and the reasons given by the mother for this condition.

In addition there was no mention of traditional beliefs, which seemed unlikely. In an attempt to try and get more depth and understanding to four questions in particular and to validate the results of the questionnaire a workshop was planned with the RWs after the evaluation. This was conducted as an informal interview.⁵⁶ This was held on the 12th May 1993 at a venue in New Crossroads. Two of the CHW co-ordinators who had been interviewers for the questionnaire were present and between them they translated the discussion. Most of the RWs were present as was the RW co-ordinator. A skilled facilitator was present to facilitate the discussion.

At the workshop the RWs were told a number of the results of the evaluation. They were then asked three questions in turn and asked to respond to these as mothers of disabled children themselves.

After this they were told the results obtained in the evaluation and asked why they thought the mothers had responded as they did.

The RWs were asked to respond to the following questions:

1. Why does your child have a problem?
2. How did you feel when you first realized that your child had a problem?
3. What do you think your child will be like this time next year?
4. How do you feel about your child now?

It was felt that for the RWs to respond to question 4 in a big group may not have been easy, as it required people to talk openly about their present feelings. Although the RWs were not asked specifically about their present feelings for their child, they spoke about these feelings.

At the workshop the RWs indicated that the mothers had responded superficially to questions which required them to expose their feelings about having a disabled child and their belief as to why they had such a child. The RWs identified a number of reasons for this, all of which question the validity of these specific answers.

Firstly, it was noted that interviewers had limited skills in drawing out information from the mothers they were interviewing. In addition the mothers did not know the interviewers and therefore felt unable to trust them with in depth feelings about their disabled child. Due to this lack of trust some of the mothers may have hidden information from the interviewers.

Secondly, the mothers may not have been clear about what the interviewers were going to do with the information. In many cases mothers are expected to expose their feelings to different people in the health and welfare services (social workers in particular). At

the end of the day the mother does not appear to get anything out of this. This makes her reluctant to expose her feelings yet again.

Thirdly, the interviewers had a limited knowledge and understanding of cerebral palsy and did not have the skills to encourage mothers to talk more if they gave a vague answer.

Finally, the mothers may have felt that as the interviewers came from a Western medical project the answers required of them were in the medical paradigm. The mothers may have been scared to open up and talk about Xhosa medicine and witches. Possibly if these questions had been posed to a group of mothers the real stories "at the back"* would have come out. This theory is supported by the responses to the question asked about which other sources the mothers had sought help from for their children. Only six mothers said they had been to a witchdoctor, whereas it is clear from informal discussions that many more do so.

6.1.4. The In Depth Interview of the Rehabilitation Workers.

A. The aetiology of the condition.

Because of the superficiality of some of the answers, an in depth interview of the RWs enabled the quality of some of the data to be enhanced. In the questionnaire the interviewers asked the mothers about their understanding of the aetiology of their child's condition. 11 (23%) of the mothers said they did not know, but the rest of the mothers gave an answer within the medical paradigm. The answers the RWs gave were detailed, graphic and full of emotion.

* The phrase, "at the back" was mentioned during the workshop with the RWs. They were referring to the mothers hiding what they really think and feel.

They all described the aetiology of their child's problem within the paradigm of traditional understanding.

Bewitchment was a common theme and graphic stories of the child being bewitched by another woman in the community, the child seeing a black snake or gogga, or an evil spirit entering the child were described. One of the disabled children is one of twins and the traditional belief that one twin is lazy and the other clever as it has taken the lazy ones thoughts were described. One of the RWs described how she knew the child was bewitched, but did not take her to a traditional healer as she knew he would agree. He would name the person who had bewitched her child and she feared her husband would then go and kill this woman. Even now she fears he will dream who it was who bewitched their child and go and kill this woman. As she has been unable to resolve this she still believes her child is bewitched and that it was this child who was responsible for killing her next two infants by kicking them.

Given the training the RWs have had it could have been expected that they would have described the aetiology in medical terms. Possibly due to knowing and trusting people at the workshop they were able to describe the stories "at the back." The beliefs expressed by the RWs are more likely to represent those which mothers really believe in.

It was interesting to note the complex relationship between the three different belief systems, the traditional belief system, the medical model and Christianity. One RW whose child contracted tuberculous meningitis took her child to hospital where she was for some time. During this time she went to a witchdoctor who told her a particular woman had bewitched her child. She expressed anger towards the person bewitching her child and anger at God. At the

same time she asked God for help to deal with her anger towards the person bewitching her child.

B. Initial feelings of the mother.

The RWs responses to the initial feelings they experienced when they realized that their child had a problem provided more detail to the similar feelings of the mothers in the survey. The RWs spoke of initial feelings of denial, pain, anxiety and sorrow:

When the doctor first told me of the problem with my child, I didn't even want to listen, I didn't want to hear it. I was worried sick.

Another commonly expressed feeling was confusion.

My child was born fitting and wouldn't take the breast. I was confused and didn't know what was happening. I had to take the child to hospital. At the hospital there were eight doctors around the child. I felt very confused.

All of them expressed in some way an acceptance of their disabled child.

I felt confused, hurt and disappointed, but I also felt that as long as I had the child it didn't matter, as this was my first child.

However feelings of anger towards God and doubt whether he actually existed were expressed.

I am cross with God with giving me this burden.

The RWs all acknowledged that having a disabled child is a heavy burden to bear, and the one RW spoke of her husband's abuse of her because she had a disabled child. He blamed her for their child's

disability saying it was because she was not faithful to him and had had so many boyfriends.

All the RWs except one expressed hope based on some improvement they had seen in their child over time.

One of the RWs expressed that she still feels pain and sadness when she is alone with her child and a sense of loss when she sees other children the same age playing as this is what her child should be doing. She had never thought that her child's death would be a relief to her.

If she died I would cry until I was *amper dood**.

C. Hope for the future.

The majority of the mothers said that they felt their child would be better in a year's time. This compares favourably with results from the evaluation of the Nairobi Family Support Service (NFSS).²⁹ In the NFSS evaluation 60% of the parents interviewed felt their children had the potential to do more and could join a regular school with effort. In the Sri Lanka evaluation the majority of the parents interviewed were realistic about their child's potential development.⁴⁴

It was surprising that the majority of mothers were hopeful about their child's condition given the severity of most of the conditions. The workshop with the RWs provided some explanation to this finding. The mothers see their child as a whole (to a far greater extent than the evaluator) and see any development in the child as improvement and a reason to hope. Many of these improvements are due to the

* Afrikaans expression meaning "almost dead".

normal development of the child and may have little to do with the work of the RWs. For example, a child which seems to be getting tighter and tighter to the therapist, is seen to be improving to the mother as he now turns his head to the door if he hears someone coming in. This possibly also explains why 45 of the 48 mothers think that the exercises the RW does with her child are helpful.

A small minority of mothers, mostly with children over five years or with severe disability had limited expectations of improvement. The mothers response is understandable as the condition of these children is unlikely to improve and is usually static.

A substantial number of mothers are not realistic about their child's potential. It may indicate that these mothers have not come to terms with the severity of the condition of their child.

6.2. STRENGTHS OF THE REHABILITATION WORKER PROJECT.

The two objectives of the evaluation were to evaluate the RW project from the perspective of the caregivers and that of the therapists. Here the strengths of the RW project will be identified from both the perspective of the caregivers and the therapists.

6.2.1. Strengths from the Caregiver's Perspective.

The responses of the mothers to all questions about the RWs were positive. The mothers perceive that the RW project is not just to teach them activities, but that advice, linking with other health services and support are as important as the exercises. In comparing the RWs to physiotherapists at a tertiary level hospital in Cape Town 58% of the mothers felt that they communicated more easily with the

RW and 81% said the RW treated their child the same if not better than the therapists.

A: Children have progressed.

36 (75%) of the mothers said that their child had improved, 23 (45%) a lot and 13 (27%) a little. In the Nairobi Family Support Service evaluation 80% of the parents interviewed felt that their children had progressed.²⁹ In the Zanzibar evaluation all the parents felt that their child had progressed since the start of the project, although in some cases this progression was very slow.³⁰

It has been argued that RWs spend too much of their time with severely disabled children with multiple handicaps, as their chances of being rehabilitated are so remote. (A number of children included in the SACLA evaluation would fall into this category). However these families really need the support of the RWs. Saunders and Zinkin⁴⁵ in the evaluation of the Kwibenzi programme in Kenya point out that the credibility of the RWs in this community has been increased as the RWs have considered these children as rightful members of the community with special needs. Although the intervention of the RWs may have a minimal long term effect on the child's disability, they can significantly improve the family's mental health.

From the responses of the mothers in the present evaluation, the time the RWs have spent with severely disabled children has certainly been worthwhile. The mothers feel both physically and emotionally supported and this has helped them cope much better with their child.

B: Meeting other mothers and their disabled children.

Events organized by SACLA at which mothers had met with other mothers of disabled children have played an important role in helping mothers cope with their disabled child. Two mothers spoke of how their initial contact with SACLA had helped them come to accept their disabled child and one mother mentioned how she came to a Christmas party organized by SACLA and saw many children with different disabilities. She felt very relieved that there were other children who were disabled.

Similarly, in the evaluation of the Zanzibar CBR programme a number of mothers said that through the different activities of the programme they had come to realize that they were not the only mothers to have a disabled child.³⁰ This had given them a more positive attitude to their child.

Linking mothers who have disabled children together is a valuable function of the work the SACLA RW project does. Functions like the annual Christmas party obviously have benefits far greater than expected.

6.2.2. Strengths from the Therapists Perspective.

The exercises and activities the RWs are teaching the caregivers are being remembered and performed well by the caregivers. Exercises taught by the SACLA therapists to the RWs who then taught the caregivers were done better than those taught by other sources. 59% of the caregivers remembered all the activities that needed to be performed. For the average performance score 79% of the caregivers scored either 4.0 or above. During the carrying out of these activities, the children are being treated holistically. This

suggests that the home visiting programme of the SACLA RW project is appropriate, accessible and acceptable to the community of disabled children and their caregivers.

Although the mothers expressed that they were confused by different organizations teaching them different exercises, they performed exercises well and remembered most of the exercises.

The fear of over-emphasis on physical treatment was not borne out by the evaluation. The two key objectives of the RW project to support the mother and treat her child are being achieved. For example, when asked what had helped them manage with their disabled child, 46% of the mothers said the RWs had helped them. 20% of these mothers said it was the exercises of the RWs and 25% of these mothers said it was the advice of the RWs that had helped them.

The results of the Zanzibar CBR programme evaluation were different.³⁰ Most of the parents felt the RWs visited them to work with their child, not to support the parents and assist them in caring for their child.

6.3. WEAKNESSES OF THE REHABILITATION WORKER PROJECT.

The evaluation also identified a number of weaknesses.

6.3.1. Weaknesses from the Perspective of the Caregivers.

13% of the mothers said that nothing had helped them manage with their disabled child and 27% of the mothers said that their children had not improved since the RW started working with their child. These reflect on the work of the RW project to a certain extent, but are also an indication of the high expectations mothers have for their children and desire to see immediate change.

Only 48% of the mothers speak to the RW about their problems. Some mothers said they did not speak to the RW as they did not know what to say and others said that they did not speak to the RW as they did not think she could help them.

6.3.2. Weaknesses from the Perspective of the Therapists.

A number of weaknesses were identified by the therapists. The active involvement of the child was limited by two factors, the position used for activities and the time the mother allowed for the child to respond. As a result many of the activities were performed by the caregiver on the child instead of the child being actively involved.

Facilitating language development was not adequately incorporated into the activities by many of the caregivers. Very few daily living activities were demonstrated to the therapists and no mothers mentioned that these are included routinely in the day.

Specific exercises to the arms or legs or a specific joint were not well done and often exacerbated the child's condition. In addition the caregiver then focussed on the specific exercise and forgot about the rest of the child.

Poor communication was responsible for five problems which the evaluation highlighted. (i) The mothers were unable to prioritize activities. Only 33% of the mothers were able to prioritize two activities. (ii) The mothers were unable to progress the activities in a logical sequence. (iii) Exercises which have been discontinued by the therapists were still being performed by the mothers. (iv) The caregivers were not involved in discussing the major problems of their child, setting objectives and planning activities to address

these problems. (v) The RWs records were not adequate or up to date.

In the analysis it became clear that in the two tests used to compare the performance of the caregivers RWs number 8 and 9 were consistently weaker than the others.

6.4. IMPLICATIONS AND CONCERNS FOR THE REHABILITATION WORKER PROJECT.

A. Maternal Understanding of the Aetiology and Prognosis of the Disabled Child.

As the in depth interview with the RWs made clear, most mothers understand the cause of their child's condition within the paradigm of the traditional belief system. This understanding has to be integrated into the RW project to ensure that the services provided by the project are meaningful.

B: Active Involvement of the Child.

60% of the activities were performed with the child in lying, so that the active involvement of the child was limited. The therapists, RWs and caregivers should be encouraged to place the children in positions from where they can be more actively involved.

Most of the children were not given time to respond to the stimulation or activity. Much of the value of the activity is lost if the child is not given time to respond. If given time to respond, the active involvement of the child would be the natural progression of most of the activities.

C. Language Development.

The RWs do not have confidence and skills to perform and teach activities which would stimulate language development. They need further training to give them the confidence and skills to be able to demonstrate and teach language development skills to mothers.

D. Daily Living Activities.

The RWs need extra skills in identifying daily living activities and activities in the home or garden which could be used to develop the child's independence. This would involve teaching task analysis where a task is broken down into small attainable steps. Each step is mastered in turn before they are linked and the activity is performed by progressing from one to the other.

E. Specific Exercises.

Very specific exercises were not well done and often exacerbated the child's condition. More general activities where the child was positioned for play or to perform a functional activity were performed much better. Therefore general activities involving the whole child are the activities of preference.

F. Detailed Baseline Data.

Good baseline data is needed for each child with a full medical, emotional and psychometric assessment together with detail of the child's level of performance. From this the child's major problems can be identified with the therapist, RW and caregiver working together.

Each RW needs to have up to date reports of the problems of each child, the objectives set and activities planned. The reports must be up to date and include dates when activities are mastered and new activities planned.

Part of the problem with communication is that writing notes in people's homes by the RWs has not been encouraged. Part of the reason for this was to avoid a patient-doctor type relationship. However, the major problem is the lack of discipline by therapists to ensure the RW is clear about the problems, objectives and activities, has written these down, has communicated them adequately to the mother and keeps all notes up to date.

G. Communication

The caregivers are involved in performing activities and are performing these well. This can be built on so that the caregiver is also actively involved in setting appropriate long and short term objectives and planning activities to achieve these objectives. Any changes must be discussed with the caregiver.

On arriving at a child's house the RWs should ask the caregiver what she has been doing with the child since the last visit, how the activities have been going and whether there has been any progress. With the caregiver these activities can be reviewed and new activities planned and taught to the caregiver. The frequency and duration of the activities can also be discussed.

By involving the mother in planning and continuing to inform her of any changes, the problems resulting from poor communication will be overcome.

H. Mothers as the Prime Caregivers.

In general the mothers performed less well than the caregivers who were not the mothers. The caregivers were usually older relatives.

Elderly more mature relatives possibly have more patience than young mothers and are prepared to spend more time with the disabled child doing regular exercises and activities. Often young mothers are expected to be economically productive as well as look after disabled children, whereas elderly relatives have only one responsibility and that is to look after children.

A further possible reason is that mothers find it very difficult to perform activities in working with their child if they sense that their child is in any discomfort or pain.⁵⁷

Generally the older mothers scored the best and for three outcome indicators there was an age trend. They are probably a similar group to the older relatives. They are more mature, not expected to be economically active and do not have small children to look after.

I. At Risk Groups.

Using the different outcome indicators certain categories of mothers were identified as being less likely to perform well with regard to the outcome indicators so that their children are at risk. Those identified as being in at risk categories were:

- a) Mothers in the 15 - 24 and 25 - 34 age categories.
- b) Caregivers who forget activities. Not only do they forget activities but those that they remember are performed badly.
- c) Mothers who are unrealistic about their child's condition.
- d) Certain caregivers are unresponsive. The RWs appear to have identified this group of caregivers and visit them twice a week. However, although the RWs are visiting them twice a week they are still performing the exercises badly.

- e) Children between 3 and 5 years old are at risk. This is possibly due to the fact that children younger than three are easier to treat as they are often not as tight and stiff as older children and children older than five are easier to treat and more rewarding as they are more able to respond and play.

Within the RW project attention needs to be focussed on these at risk groups of mothers and children. The RWs need to be aware of the immaturity of the 15 - 24 year old mothers and the strain mothers in the 25 - 34 age category having to cope with other young children as well as being economically active. The RWs need to ensure they are very supportive of these mothers, visiting them frequently and being available.

It is these mothers who might benefit most from a support group as they will then have some time when they are not having to take responsibility for their disabled child. This might help enable them to cope better in the long term. Much time needs to be spent with these mothers using the opportunities she presents to talk about the child's problems, the objectives of the activities and the activities planned.

Besides spending more time with the mothers, the RWs also need to spend extra time with the children of these mothers as these children need attention and treatment which their mothers may be unable to provide.

J. The Frequency and Duration of the RWs Visits.

The results from this analysis indicate that visits by the RWs of an hour or more are of more benefit than shorter visits. Visits more than twice a week did not seem to improve the outcome indicators. This might suggest that visits more frequently than once a week are

of no benefit, or it might suggest that the RWs have identified unresponsive caregivers and are visiting them more frequently.

With regard to developing guidelines for home visits, visits of at least an hour are preferable. However, further information needs to be collected before recommendations can be made regarding the frequency of visits.

K. The Lack of Space in Home Based Rehabilitation.

The lack of space in home based rehabilitation is often a problem. Positioning a child in a small shack with no furniture other than a bed and cupboard has problems. A number of children tried to write or draw kneeling on the floor resting on their elbows. This is a difficult position for anyone to write in, especially a child who has increased tone and abnormal movement patterns.

It is not clear how this problem can be overcome. Ideally these children need to be at a special school or creche where they would be taught and supervised daily as they carry out a number of different activities. The RWs could not provide this kind of service as well as have the responsibility of visiting over 40 disabled people in their homes monthly.⁵⁸

L. Toys Used in Activities.

The RWs carry a small number of toys with them as they do home visits. These are used in the activities. This is clearly a problem for the caregiver to try and perform activities in the absence of these toys or suitable replacements. In addition the number of activities performed with a small number of toys is limited and a few activities are performed routinely. In the evaluation of the Sri

Lanka CBR programme⁴⁴ the RWs felt that a shortage of equipment forced them to be routine.

A toy making workshop could be held in each area to which all caregivers are encouraged to come. The emphasis of the workshop would be on using unused bits and pieces (usually classified as rubbish) available in the house or community to make toys. The aim of the workshop would be to introduce caregivers to the concept that they can make toys out of bits and pieces which are often left lying around the house and community as rubbish.

The RWs must be encouraged and provided with the skills to do activities in the home or garden which do not require specific toys. These will then be conveyed to the caregivers.

M. Weak RWs.

The therapists and RW co-ordinators who spend time with the RWs who were identified as being weaker than the others have been informed of these results. They were asked about the performance of these two RWs on a routine basis. The opinions expressed confirm the findings of the evaluation. Accordingly the therapists and RW co-ordinators must make the effort to teach skills patiently and consistently providing positive feedback to these two RWs. Whenever possible they must be included in extra training sessions. In addition these two RWs need assistance in planning their home visiting schedule on a weekly basis and clear guidelines on the frequency and duration of home visits.

6.5. FINDINGS OF THE SACLA EVALUATION COMPARED TO OTHER RESEARCH.

6.5.1. Household Occupancy.

The average number of people living in each house was found to be 5.13, which is slightly higher than other studies undertaken in the Western Cape. The Development Action Group⁵⁹ works on an average of 5 people per house and Cooper et al⁷ in their study in Khayelitsha had an average household occupancy of 4.9. A possible reason for the slightly higher household occupancy may be that mothers with disabled children often move into houses with their relatives in their need for support in caring for their disabled child.

6.5.2. The Role of Fathers.

In most societies child care is the responsibility of women. In this evaluation the primary caregiver was a woman in every case. Only four mothers mentioned that the help and support of the father had helped them to cope with the trauma and burden of having a disabled child. At the workshop with the RWs in which in depth feelings were discussed, one of the RWs spoke at length about her husband's abuse of her because of their disabled child. Only one variable - language development of the disabled child - was significantly better if the father was present. This result could imply that fathers do contribute by spending time interacting with their disabled children. On the other hand this result may be spurious.

6.5.3. Types of Cerebral Palsy.

Given the possibility of some misclassifications and the fact that the sample size was small, it is still beneficial to compare the types of cerebral palsy seen in this study with other studies based in Africa (Table 6.5.3.). In the SACLA evaluation 22 (46%) of the children were spastic quadriplegics. Studies done in the Ciskei⁵¹ and in Nigeria⁵² also had relatively high proportions of spastic quadriplegics. A study done in Tanzania⁵³ had a low percentage of spastic quadriplegics but the highest percentage of spastic diplegics.

As might be expected given the socio-economic profile, geographical area, traditional belief system and use of traditional as opposed to Western medicine the results of this study are most similar to those of the study based in the Ciskei.

TABLE 6.5.3. COMPARING TYPES OF CEREBRAL PALSY WITH OTHER AFRICAN STUDIES*.

| Place | SACLA | Ciskei | Cape Town | Nigeria | Tanzania |
|--------------|-------|--------|-----------|---------|----------|
| | 1. | 2. | 3. | 4. | 5. |
| | % | % | % | % | % |
| Spastic | | | | | |
| Quadriplegia | 46 | 57 | 14 | 37 | 10 |
| Diplegia | 8 | 5 | 25 | 11 | 64 |
| Hemiplegia | 10 | 21 | 29 | 20 | 6 |
| Hypotonic | 15 | 6 | 1 | 13 | 4 |
| Athetoid | 10 | 3 | 18 | 2 | 12 |
| Mixed | 7 | 7 | 10 | 16 | 4 |
| Other | 4 | 1 | 3 | 1 | 0 |
| Total | 48 | 211 | 389 | 104 | 50 |

Key:
 1. SACLA RW evaluation
 2. Power 1988.⁵¹
 3. Molteno and Arens 1980.⁶⁰
 4. Izuora and Oroko 1981.⁵²
 5. Makwabe and Mgone 1984.⁵³

* This graph follows that of David Power.⁴⁷

6.5.4. Aetiology of Cerebral Palsy.

TABLE 6.5.4. COMPARING AETIOLOGY OF CEREBRAL PALSY WITH OTHER AFRICAN STUDIES

| Study | Pre Natal % | Peri-Natal | | | | Post-Natal | | | | | Total | |
|------------|-------------------|------------|----------|----------|----------|--------------|----------|---------|----------|----------|---------|-----|
| | | Asp % | NNJ % | Prm % | Oth % | TBM % | CVT % | BM % | Enc % | Oth % | UK % | |
| No. | | | | | | | | | | | | |
| 1 RW Eval | 15 | 27 | 8 | 6 | 2 | 11 | 6 | 6 | 2 | 0 | 17 | 48 |
| 2 Ciskei | 2 | 33 | 1 | 7 | 6 | 8 | 4 | 6 | 2 | 1 | 33 | 211 |
| 3 C.T. | 19 | 15 | 3 | 18 | 1 | -----22----- | | | | | 20 | 331 |
| 4 Nigeria | 16 | 31 | 23 | 3 | | -----17----- | | | | | 10 | 104 |
| 5 Tanzania | 0 | 24 | 12 | 0 | 0 | 0 | 0 | 0 | 0 | 60 | 4 | 50 |

Key:

UK = unknown

Asp = Asphyxia

NNJ = Neonatal Jaundice

Prm = Prematurity

Oth = Other

TBM = Tuberculous meningitis

CVT = Cerebral vein thrombosis

BM = Bacterial meningitis

Enc = Encephalitis

1 RW evaluation

2 Power 1988.⁵¹

3 Molteno and Arens 1980.⁶⁰

4 Woods 1983.⁶¹

5 Makwabe and Mgone 1984.⁵³

There is a raised incidence of asphyxia in socially deprived communities which may be due to limited access to obstetric care or because of an ill-understood placental condition which appears to disappear with economic advancement.⁶¹ Power found that the greatest number of children suffering from asphyxia had spastic quadriplegia whereas Molteno and Arens⁶⁰ noted that asphyxia resulted mostly in spastic hemiplegia.

The relatively high incidence of neonatal jaundice (8%) reflects the poor access to health care. The majority of the children seen by the SACLA RW project are born in rural areas of the Transkei and Ciskei where access to medical services is limited. The high incidence of tuberculous meningitis (11%) is not surprising given the endemic proportion of tuberculosis present in deprived socio-economic communities in the Western Cape. The incidence of cerebral vein

thrombosis and prematurity might be expected to be higher in a developing world situation.

Izuora and Okoro⁵² noted that 21% of the children in their study had microcephaly associated with birth trauma or a congenital condition. A number of the children seen by the RWs have microcephaly, but because it is not routinely documented on the child's records it would be inaccurate to compare these figures with those of the Nigerian study.

Quadriplegics of all types are the more severely intellectually handicapped and visually impaired.⁶⁰ The high incidence of cerebral palsy and severity of the children's conditions would be considerably reduced if there was better access to health services and people were not living in such impoverished conditions.

6.5.5. Maternal Perception of the Needs of their Disabled Child.

This study highlights the needs perceived by parents of disabled children. Financial assistance, mobility and exercises were found to be the dominant needs in this evaluation. It is clear that these needs overlap substantially with that found by other researchers.¹⁷ In contrast, disabled adults tend to be more concerned with income-generating activities, lack of family and social integration, participation and representation in community affairs and security needs.²²

6.6. CONCLUSION.

This chapter has been concerned with a discussion of the results of the major and minor questionnaires as well as qualitative information gained in the in depth interview with the RWs. It was noted that because of the small sample size, the difficulty in observing some of the requirements, and the "hiding" of information by the mothers, some of the results must be considered to be provisional, and others need to be discounted. However, the in-depth interview improved the quality of much of this data.

The key strengths and weaknesses of the RW project were identified from the perspective of the caregivers and the therapists and the implication for these findings and the concerns they raise were discussed in some detail. Finally, comparisons were made with other similar research.

CHAPTER SEVEN: CONCLUSION.

In this final chapter, the attainment of the objectives of the evaluation is considered. The significant findings of the evaluation are identified with strategies for action in the RW project itself. Finally, the implications for CBR in general are drawn out.

7.1. REVIEW OF THE PURPOSE AND SPECIFIC OBJECTIVES OF THE EVALUATION.

The first purpose of the evaluation (4.1.1.) was to identify the strengths and weaknesses of the SACLA RW project, and this has been achieved, as the discussion in Chapter Six makes clear. The second purpose was also achieved in that through a discussion of the socio-economic context, the principles and structure of the project and the results of the evaluation it has been demonstrated that SACLA RW project is an effective model for local CBR projects.

In order to meet the two-fold purpose of the evaluation, seven specific objectives were identified in Chapter Four (4.1.2.). These objectives have been fulfilled.

1. A detailed profile of the disabled children and their families was developed.
2. The maternal understanding of and attitudes to the disabled child was determined, particularly through the qualitative interview with the RWs where strong feelings of love, attachment and pain were elicited.
3. Both the mothers and caregivers were overwhelmingly positive about the emotional and other support they get from the RWs and the effect of the activities on their children.

4. The service of the RWs was highly regarded and compared very favourably with that of the therapists.
5. While more than half of the caregivers remembered all the activities the child needs, only one third of the mothers were able to prioritize the activities.
6. The large majority of caregivers performed the exercises very well.
7. Socialization and cognitive development were integrated by the vast majority of the caregivers into the activities although concerns were raised about the active involvement of the child and language development.

7.2. IMPLICATIONS OF THE EVALUATION FOR SACLA

Our discussion in Chapter Six, has made clear that the results of this evaluation have a number of important implications for the SACLA RW project. In summary these are:

1. More attention should be given to identifying problems, setting objectives and planning activities so that the caregivers have a clear understanding of the objectives for their child and the activities planned to achieve these objectives.
2. The RWs need to have up to date reports of the problems of each child, the objectives set and activities planned. The reports must include the child's latest accomplishments and subsequent changes in problems, objectives and activities.
3. Children must be actively involved in the activities by using positions which will encourage them to be involved and giving them time to respond.
4. Caregivers must be involved in identifying their child's problems, setting objectives and planning activities and the frequency of the visits by the RWs.
5. The RWs need further training with regard to stimulating language development and communication in their routine work with children.
6. Further training is needed by the RWs on the inclusion of activities based in the home or garden into their daily work with children.

7. Certain groups of mothers and children have been identified as being at risk. A common strategy needs to be developed with regard to visiting these families more frequently, being available to provide emotional support for the mothers and spending more time with the children.
8. Guidelines need to be developed within the RW project on the frequency and duration of home visits.
9. Weak RWs have been identified. Ongoing training, close support, supervision and assistance with managing their home visiting programme are the strategies which have been suggested to assist these RWs.

7.3. METHOD OF IMPLEMENTING CHANGES.

To address the problems that the evaluation has highlighted a workshop will be held with all the RW project staff. The problems identified by the evaluation will be described. Together the RW project staff will prioritize these, establish objectives, plan action and set time limits for the implementation of these changes.

7.4. FURTHER AREAS OF EVALUATION.

The scope of this evaluation was limited and only the home visiting programme was evaluated. Many other aspects of the project could be evaluated, the training of the RWs, the ongoing training and support of the workers, links and referrals to the health and welfare sector and links with special education and vocational institutions and the RW project from the perspective of the RWs.

It has been suggested that a future health service in South Africa include grassroots community health workers and RWs on a national basis. A cost-benefit survey of the SACLA RW project could be undertaken. Using the SACLA RW project as a model with ratios of

the number of disabled people to RW, the number of RWs to co-ordinators and the number of co-ordinators to therapists could be worked out, these figures could be extrapolated to determine whether this cadre of worker is affordable for the country on a national basis.

7.5. IMPLICATIONS FOR CBR.

The findings of this study provide further evidence that at a local level CBR is an effective and legitimate response to the needs of disabled people in less developed regions. Taken along with the findings of similar studies reviewed in Chapter Three it is clear that the development of local CBR projects should urgently be supported by the South African health authorities in the interests of disabled people and their families. It is further hoped that the specific issues highlighted by this study can make an ongoing contribution to the development of such projects both in this country and in similar less developed regions.

REFERENCES

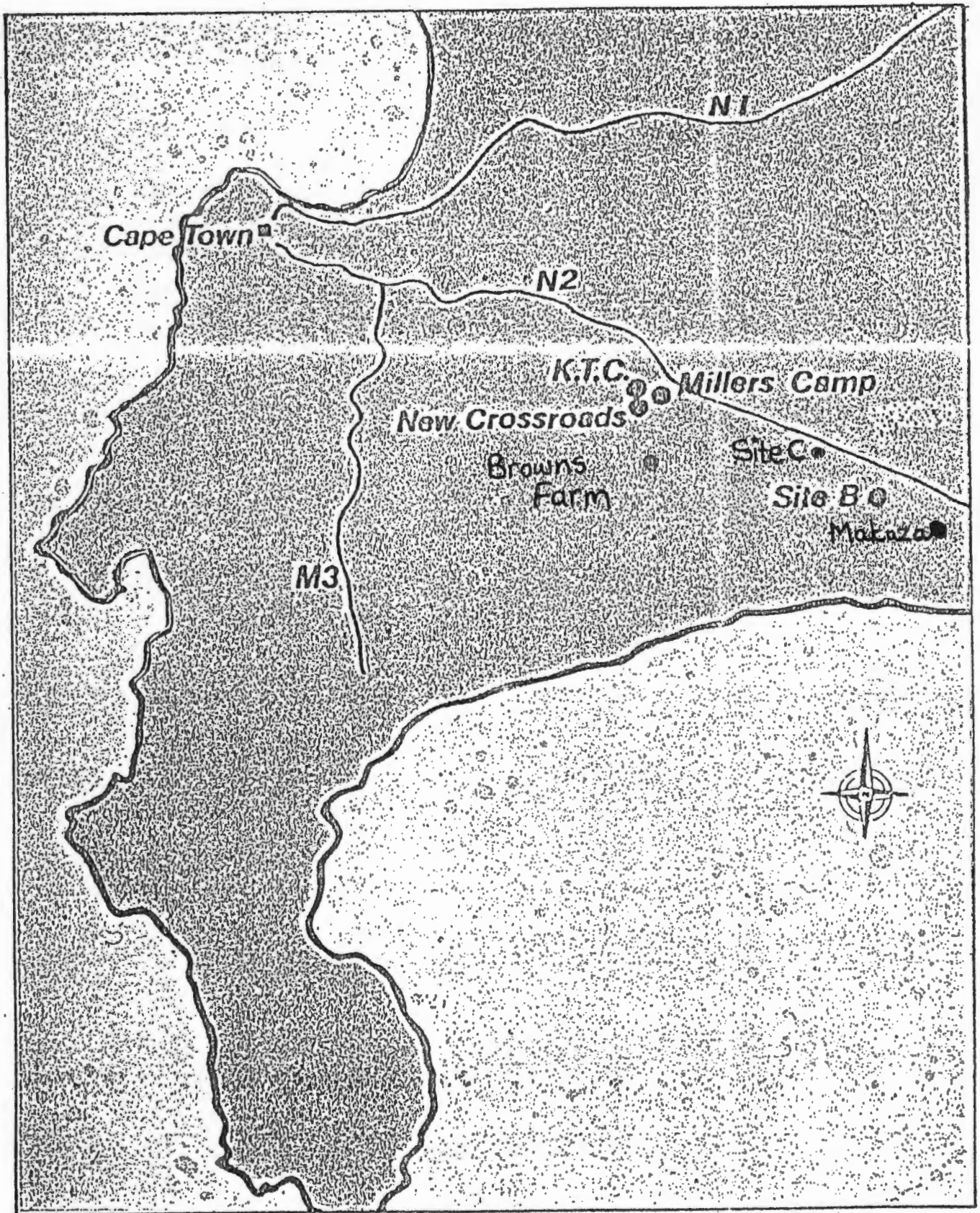
-
1. Personal communication with the Urban Research Planning Unit at UCT, Surplus People's Project, the Development Action Group, and four different divisions of the Cape Provincial Administration.
 2. Harrison D, McQueen A. *An Overview of Khayelitsha: Implications for Health Policy and Planning*. Cape Town: Medical Research Council: Health Systems Division of the Centre of Epidemiological Research in Southern Africa, 1992.
 3. Western Cape Regional Services Council; Khayelitsha - Site C Baseline Data 1990.
 4. Memorandum concerning Informal Housing by Dr. Peter Baron, Western Cape Regional Services Council; 12 June 1991.
 5. Personal communication with the Service Land Project.
 6. Mathews C, van der Walt H, Hewitson DW, Toms IP, Blignaut R, Yach D. Evaluation of a peri-urban community health worker project in the western Cape. *S Afr Med J* 1991; **79**: 504-511.
 7. Cooper D, Pick WM, Myers JE, Hoffman MN, Sayed AR, Klopper JML. Urbanization and women's health in Khayelitsha: Part 1. Demographic and socio-economic profile. *S Afr Med J* 1991; **79**: 423-427.
 8. Gugler J. (Ed.) *The Urbanization of the Third World*. Oxford: Oxford University Press, 1988.
 9. Heap M. A profile of a sample of Crossroads households and some survival strategies. Unpublished paper presented at a Centre for African Studies (UCT) Conference. July 1986.
 10. Le Roux I, Le Roux P. Survey of the Health and Nutrition Status of a Squatter Community in Khayelitsha. *S Afr Med J* 1991; **79**: 500-503.
 11. Brown M. *This Money will be Used to Bury me: The Current State of Black Pensions in South Africa*. Johannesburg: Westro, 1990.
 12. Cole J. *Crossroads: The Politics of Reform and Repression 1976-1986*. Johannesburg: Ravan Press, 1987.
 13. South African National Civic Organization (S.A.N.C.O.) was launched in Johannesburg in February 1992. It is a national civic organization aligned to the African National Congress.
 14. Political reviews, analysis, and comments from 1988 to 1993 in *The Weekly Mail*. M&G Media, Braamfontein.
 15. Personal communication with SACLA staff.

16. World Health Organization Report of an Interregional Consultation in Sri Lanka. *Community Based Rehabilitation* (RHB/IR/82.1.). Geneva: WHO, 1982.
17. Helander E. *Disabled People in the Developing Countries: Situation Analysis*. The Forum on Co-ordination of Rehabilitation Programmes. Geneva: United Nations Development Programme, 1992.
18. Loveday M, Data Collection in the SACLA Rehabilitation Worker Project. Cape Town, 1992.
19. Buhrmann MV. *Living in Two Worlds - Communication between a white healer and her black counterparts*. Cape Town: Human and Rousseau, 1984.
20. Reynolds P. *Childhood in Crossroads*. Cape Town: David Philip, 1989.
21. Loveday M. *Community Based Rehabilitation Workers - a South African Training Manual*. Cape Town: SACLA Health Project, 1990.
22. SACLA Health Project, Annexure 1: A History of SACLA, in Funding Proposal to the South African Council of Churches, February 1989.
23. SACLA Health Project, Report to British Council, February 1988.
24. SACLA Health Project, Fundraising Proposal to the Kaiser Family Foundation, June 1988.
25. SACLA Health Project, Progress Report to the Kaiser Family Foundation, April 1991.
26. SACLA Health Project, Final Progress Report to the Kaiser Family Foundation, June 1992.
27. World Health Organization Report of the International Conference at Alma Ata, USSR 6-12 Sept 1978. *Primary Health Care*. Geneva: WHO, 1978.
28. This sentiment was expressed by Black professional physiotherapists at the "Reach Out Symposium", Pretoria University, October 1990.
29. An Evaluation report of the Nairobi Family Support Services: A community based rehabilitation project. Unpublished mimeograph paper. AMREF 1987.
30. Juma F, Miles S. An Evaluation of the Community Based Rehabilitation Programme of the Organization of Disabled People of Zanzibar. Unpublished mimeograph paper. Save the Children Fund (U.K.), 1989.
31. Werner D. *Disabled Village Children*. (2nd edition). Palo Alto: Hesperian Foundation, 1988.

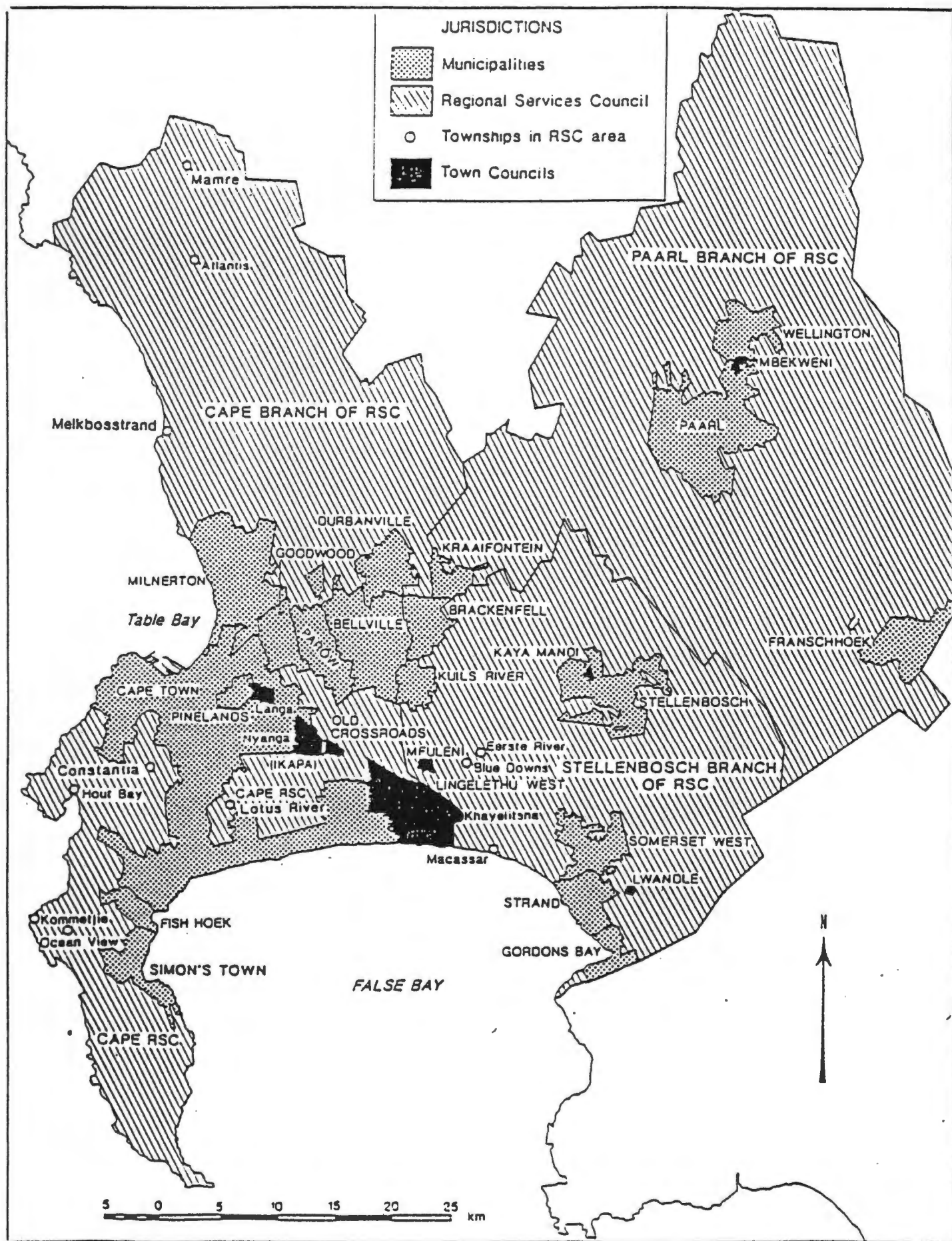
32. Disabled People South Africa (DPSA). This organization was launched in Johannesburg in 1984. In the Western Cape it was launched in July 1992.
33. Walt G. CHWs: are national programmes in crisis? *Health Policy and Planning* 1988; 3(1): 1-21.
34. World Health Organization. *Disability prevention and rehabilitation*. (Reports on Specific Technical Matters, A29/INF.DOC/1.). Geneva: WHO, 1976.
35. Momm W, Konig A. *From Community - Based Rehabilitation to Community - Integration Programmes: Experiences and reflections on a new concept of service provision for disabled people*. Geneva: International Labour Organization, 1989.
36. World Health Organization. *Health Programme Evaluation - Guiding Principles*. Geneva: WHO, 1981.
37. Murthy RS, Pruthvish S, Thomas M. Evaluation of Health Programmes on Non-governmental Organizations. *ActionAid Disability News* 1993; 4: 16-19.
38. Personal communication with Stephanie Kemp who worked at the Bobath centre for a number of years and was a tutor teaching the neurodevelopmental approach for the treatment of children.
39. O'Toole B. Community based rehabilitation for disabled children in rural Guyana. *World Health Forum* 1989; 10: 238-239.
40. Mendis P. Evaluation of a Community Based Rehabilitation Project in Tiang Giang and Ho Chi Minh. Unpublished mimeograph paper, 1988.
41. Menon PBM. Developing community-based rehabilitation services for the disabled by the primary health care approach. *Int Rehabil Med* 1984; 6: 64-66.
42. Baker P. Programmes for disabled people in south Sudan. *Physiotherapy* 1985; 75 (8): 403-407.
43. Robinson J. Care in the community: Support for informal carers of chronically ill and disabled people. *Int Disabil Studies* 1987; 9 (2): 81-83.
44. Gunawardena M, Saunders C. An evaluation of the community based rehabilitation programme Nuwara Eliya, Sri Lanka. Unpublished mimeograph paper. Save the Children Fund (UK), 1990.
45. Saunders C, Zinkin P. Evaluation of the Kwibezi CBR Programme run jointly by Action Aid Kenya, AMREF and the government of Kenya. Unpublished mimeograph paper. Save the Children Fund (UK), 1990.
46. Sebina DB, Kgosiidintsi AD. Disability prevention and rehabilitation in Botswana. *Assignment Children* 1981; 53/54: 135-152

47. Bobath K. The motor deficit in patients with cerebral palsy. *Clinics in Developmental Medicine* 1966; **23**.
48. Behrman RE, Vaughan VC. *Nelson: Textbook of Pediatrics*. (2nd edition). New York: WB Saunders, 1983.
49. Banus BS, Kent CA, Norton YS, Sukiennicki DR, Becker ML. *The Developmental Therapist*. London: Slack, 1979.
50. Reed KR, Sanderson SR. *Concepts of Occupational Therapy*. London: Williams & Wilkins, 1980.
51. Power DJD. *Asphyxia Neonatorum in a Developing World Situation*. M.D. Thesis. University of Cape Town, 1988.
52. Izuora GI, Okoro AB. Some clinical aspects of cerebral palsy among Nigerian Igbo children. *Cent Afr J Med* 1981; **27**: 155-159.
53. Makwabe CM, Mgone CS. The pattern and aetiology of cerebral palsy as seen in Dar Es Salaam, Tanzania. *East African Medical Journal* 1984; **61**: 896-899.
54. Patton M. *Qualitative Evaluation Methods*. Bev. Hills: Sage Press, 1988.
55. Katzenellenbogen J, Joubert G, Yach D. *Introductory Manual for Epidemiology in Southern Africa*. Cape Town: Medical Research Council, 1991.
56. Scrimshaw S, Hurtado E. *Anthropological Methods, Rapid Assessment Procedures for Nutrition and Primary Health Care*. The United Nations University, Tokyo. UNICEF, University of California, 1987.
57. Personal communication with Nosiseko Dlakavu a mother of a disabled child and co-ordinator of the Nonceba RW project in Khayelitsha.
58. Personal communication with Fiona Loubser, SACLA occupational therapist.
59. Personal communication with Alastair Rendall who works for the Development Action Group.
60. Molteno CD, Arens LJ, Marshall SR, Robertson WT. Cerebral palsy in Cape Town. *S Afr Med J* 1980; **57**: 823-826.
61. Woods JR. Birth asphyxia: Pathophysiologic events and fetal adaptive changes. *Clinics in Perinatology* 1983; **10**: 473-486.

APPENDIX A: DIFFERENT TOWNSHIPS IN RELATION TO CAPE TOWN.



APPENDIX B: LOCAL AUTHORITY JURISDICTIONS IN THE WESTERN CAPE.



APPENDIX C: MAJOR QUESTIONNAIRE.

FILLED IN BEFORE VISIT:

Questionnaire Number: _____

SACLA Number: _____

Interviewer's name: _____

Address: _____

Name of child: _____

DOB of child: _____

Age of child: _____

Diagnosis: _____

Date child first seen by a SACLA R.W.: _____

R.W.s name: _____

QUESTIONNAIRE

A. Introduction

1. When was the mother born? _____
How old is the mother? _____
2. Who usually looks after the child? _____
To whom did the R.W. talk to and show exercises to?

3. How many people live in this house?

4. Can you give me a list of those who cook or eat together or who share the money of the household?
(This must include the person answering the questions. List the people oldest to youngest.)

| Name | Age | Sex | Relationship to child | Marital Status | Permanent in house |
|-------|-------|-------|-----------------------|----------------|--------------------|
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |

B. To determine the mothers attitude to the R.W.

1. Does a R.W. come and work with you and your child at home?

Yes

No

Philani Site C

2. If yes do you know the name of the R.W.?

Name: _____

Tell name if incorrect.

3. Do you know which organisation the R.W. works for?

Name: _____

* 4. Why do you think the R.W. visits you?

5. About how often does the R.W. visit you?

twice a week
once a month

once a week
other _____

once every 2 weeks

6. When did the R.W. last visit you?

7. About how long did the R.W. stay in your house during her last visit?

5 mins

30mins

1 hour

2 hours

2+ hours

* 8. How did you feel after the last visit?

* 9. Is this how you usually feel after her visits?
If no, explain:

* 10. In your opinion does the R.W. come too much, too little or just right? Can you explain?

11. Since the R.W. started working with your child, has your child:

improved a lot _____
stayed the same _____
got worse _____
improved a little _____
in some ways got better, in others worse _____

* 12. Can you explain why you say this?

C. To determine the mother's understanding of the problem with her child?

* 1. In your opinion, what is the problem with your child?

* 2. Why does your child have this problem?

* 3. What do you think your child will be like this time next year?

* 4. Do you think your child will attend a "normal" school? (A school which is not a special school)

D. To find out about the mother's feelings and needs.

- * 1. How did you feel when you first realised your child had a problem?

- * 2. What do you feel about your child now?

- * 3. Do you ever talk to the R.W. about your feelings about your child? Why do you talk to her or why do you chose not to talk to her?

- * 4. Does your disabled child have needs which are different to those of other children? Explain why you said this:

- * 5. Do you as the mother of a disabled child have needs which are different to those of other mothers?

- * 6. What has helped you manage with your disabled child?

7. In what ways has the R.W. helped you, if any?

| | unprompted | prompted |
|-------------------|------------|----------|
| made appointments | _____ | _____ |
| taught exercises | _____ | _____ |
| advice | _____ | _____ |
| support | _____ | _____ |
| other (specify) | _____ | _____ |

8. Since you started seeing the R.W. have you been to see anybody else or any other service to find help for your child?

Yes

No

If yes, explain who you have seen:

9. Has your child been seen by the physiotherapists at the cerebral palsy clinic at Red Cross Hospital?

Yes

No

* 10. If yes, how do you feel the R.W.s handle your child compared to these physiotherapists?

* 11. If yes, how do you feel the R.W.s talk to you compared to these physiotherapists?

12. Have you been taught exercises by the R.W.? Yes No

Has anybody else taught you exercises? Yes No

Who was this? _____

Are you confused about which exercises to do? Yes No

13. Could you demonstrate for us the 2 activities which are most important for your child?

Activity

1. _____

2. _____

14. How often do you do these activities (listed above)

twice a day
once a week

once a day
not at all

once every 2 day

15. Do you think these exercises are important?

Yes

No

16. What do you think the exercises do for your child:

help her

make little difference

harm her

17. What is your opinion about the SACLA Rehabilitation Project?

E. Observation by the interviewer.

1. Type of house.

Formal _____
Serviced shack _____
Unserviced shack _____
Back shack _____

2. To you as the interviewer, does the child look well cared for?

washed dressed sores

3. What was the child doing when you arrived?

4. What was the child doing when you talked to the mother?

5. What do you notice about the way in which the mother relates to the child? Does she:

talk to her child _____
look him in the eyes _____
touch him lovingly _____
kiss him _____
take her time with him _____
firm _____
cross with him _____
seem to be rough _____
impatient with him _____
seem to be in a hurry _____
resent him. _____
handle him with confidence _____
other _____

APPENDIX D: MINOR QUESTIONNAIRE.

FILLED IN BEFORE VISIT:

Questionnaire Number: _____

SACLA Number: _____

Therapist's name: _____

R.W.s name: _____

Address: _____

Name of child: _____

DOB of child: _____

Age of child: _____

Diagnosis: _____

Date child first seen by a SACLA R.W.: _____

Home programme caregiver taught (from notes):

A. Observation by the Therapist.

1. To you as the interviewer, does the child look well
cared for?

washed dressed sores

2. What was the child doing when you arrived, whilst
you talked to the mother and afterwards?

3. If you have not seen the child yet ask to see it.
What do you notice about the way in which the mother
relates to the child? Does she:

- talk to her child _____
- look him in the eyes _____
- touch him lovingly _____
- kiss him _____
- take her time with him _____
- firm _____
- cross with him _____
- seem to be rough _____
- impatient with him _____
- seem to be in a hurry _____
- resent him. _____
- handle him with confidence _____
- other _____

4. Can you demonstrate the exercises, positions and handling you do with
your child?

| Position (Describe) | Problems | Activity (Describe) | Effective (Score) |
|------------------------|----------|------------------------|----------------------|
| 1. _____ | | | |
| 2. _____ | | | |
| 3. _____ | | | |
| 4. _____ | | | |
| 5. _____ | | | |

5. Is the child being treated as a whole person ie. not just a damaged part? Whilst the mother handles the child are the following areas involved in the activities?

Socialization

Yes

No

Language

Yes

No

Motor development

a) fine motor

Yes

No

P

M + c

C A

b) gross motor

Yes

No

P

M + c

C A

Self-help

Yes

No

Cognitive Development

Yes

No

B. Questions by the Therapist.

1. How often do you do these activities (listed above)

twice a day
once a week

once a day
not at all

once every 2 day

2. Do you think these exercises are important?

Yes

No

3. What do you think the exercises do for your child?:

help her

make little difference

harm her

Why do you say this?

APPENDIX E: NOTES TO ASSIST THERAPISTS WITH MINOR QUESTIONNAIRE

NOTES TO MAKE EVALUATION FORMS USER FRIENDLY.

A: Notes to Assist Therapists.

1. Introduce the evaluation to the mother before you start. Explain that we are doing an evaluation of our work at the moment and that during our visit we will ask the mother to do exercises, watch her and then fill in a form. It is not a test for the mother, but a test for us and the R.W.s

2. Question 4 - Scoring

0 - No clue

1 - Poor

2 - Got general idea, fair, but 3 things wrong, so ? benefit.

3 - Good, 2 things wrong

4 - 1 thing wrong

5 - Perfect, no rather very good

Accurate scoring will be vital for the analysis.

In scoring, explain why marks have been deducted.

eg. Prone lying 3, because, towel under tummy and not under chest and child asymmetrical.

3. Bear in mind that the mother is not treating her child in the perfect environment with the best equipment. In scoring, take this into account. Remember Siyavuya in standing, his upper trunk and head were not in a good position, but Nosango treats him with her daughter and both are kept fully occupied controlling his lower limbs and trunk. They may not have a 3rd person to control his head or a piece of furniture the right height to assist them.

4. The time spent in each position comes into scoring the activities. Time is needed in each position to achieve maximum potential in this position. Think of Siyavuya in sitting facing sideways between Nosango's legs. She could have used this position to a far greater extent.

5. Question 5 Socialization

Interaction between mother and child. Remember Nosango talking away to Siyavuya.

6. Question 5 Language

Imagine yourself at the child's level, is communication by the child being actively worked for? This we have decided for this evaluation in language.

Language we have defined as:

mouth awareness

imitation of sound

using environment to communicate - pointing

awareness of body parts

7. Question 5 Motor development

3 levels for both fine and gross motor development

P = Passive.

Mother is doing the exercise on the child, with no interaction with the child.

M + c = Mother's activity with child involved, although he might not be able to do the exercise in any way.

C A = Child active

The mother gives the child a chance to actively respond. She gives him time to respond.

8. Question 5 Self Help

Any attempt to develop personal care, washing eating, dressing, toilet training, brushing teeth, brushing hair, child drools can he wipe his own mouth, child's nose runs can she wipe it.

9. Question 5 Cognitive Development

This may involve any of the following, concentration, looking at a rattle or toy, listening to a rattle, learning or identifying colours, numbers, shapes, body parts, spatial concepts (in 3d eg. building blocks), pre-writing skills

Siyavuya looked at a rattle, concentrated and appeared to listen, so Nosango did work on his cognitive development.

B: Questions to mother from section B of the therapists evaluation form. These have been translated into Xhosa, so that the R.W. can ask the mother.

B.1. Uyenza amaxesha amangaphi le misebenzi (ibalwa ngentla)?

kabini ngosuku _____
kanye ngosuku _____
kanye emvakwentsuku ezimbini _____
kanye ngeveki _____
andiyenzi tu _____

B. 2. Ucinga ukuba ezi-exercises zibalulekile?

Ewe

Hayi

B. 3. Ucinga ukuba i exercises:

ziya mnceda umntwana wakho
zenza umahluko omncinci
ziyamonakalisa umntwana oku

Kutheni uthetha oku?

APPENDIX F: WORKSHOP WITH CO-ORDINATORS.

WORKSHOP WITH CO-ORDINATORS

Aim:

1. To equip two co-ordinators with interviewing skills, so that they can interview mothers and administer the questionnaire.
2. To introduce the need for evaluation and the basic research process to the co-ordinators, so passing on ideas which the co-ordinators may use at a later stage to evaluate the work they do.

Process for the day:

- | | |
|---------------|---|
| 8.30 - 8.45 | Background of the rehab project. |
| 8.45 - 9.00 | Objectives of the evaluation. |
| 9.00 - 9.15 | Outline research process. |
| 9.15 - 10.00 | Interviewing skills |
| 10.00 - 11.00 | Go through questionnaire. |
| TEA | |
| 11.00 - 12.00 | Role plays using questionnaire. |
| 12.00 - 1.00 | Practise interviewing each other. |
| LUNCH | |
| 2.00 - 4.00 | Interview a mother of a polio child in the community. |
| 4.00 - 5.00 | Report back and comments on questionnaire. |

1. Background of the Project.

A brief summary of the project was given, when it was started, our aims and why we want to evaluate our work.

2. Research process.

2.1. Set objectives

The initial aims of the R.W. project were to:

- a) inform the mother about the condition of her child
- b) teach her exercises to prevent the child's condition from deteriorating
- c) support the mother

Now four years later on we want to evaluate our project from the point of view of the mothers of the disabled children that we see.

2.2. Plan

To evaluate the project from the point of view of the mothers of disabled children, we plan to interview 50 mothers. These 50 mothers will all have children with brain damage, as this is the most common condition that we see. Mothers seen by the 10 different R.W.s will all be seen. 10 of the 50 mothers have been seen by the R.W.s for less than 3 months.

There will be two parts to the questionnaire, the major part in which two co-ordinators will interview the mothers and then the minor part in which the rehabilitation therapists will ask the same group of mothers to play, handle and treat their child.

Initially we thought that 2 co-ordinators would do the interviewing. The co-ordinators felt 3 co-ordinators should be involved as geographically there are 3 areas. Three interviewers would go quicker and this was a concern as they were not able to do their work during this time.

2.3. Draw a sample

We have almost 400 disabled children in the project. There is no ways we can interview all these 400 mothers. A smaller group of mothers can be interviewed, but it is very important that this group is not biased.eg. We could go and chose the 50 keenest mothers that we see. They would all say the project is wonderful and the R.W.s amazing, but this would not be a true reflection of the project. By using a sample group we hope not to be biased and to get a true reflection of the project.

So how did we chose the 50 mothers we have chosen to be interviewed?

We decided to interview 50 mothers as this is the number recommended to me by people from CERSA who are experts in the field of research. To chose which 50 people should be seen, each R.W. was given a list of the children they see with brain damage. They told me which of these children were in Cape Town and at home at the moment.

These children were numbered. Using a special set of numbers called a randomn number table, 50 of children were chosen. The more children a R.W. sees, the more of these children will be included in the evaluation.

To demonstrate how to draw a sample, an example was given on newsprint and the co-ordinators were shown how a randomn number table is use.

If these 50 mothers are chosen, only these 50 can be used. We will make the results less true and more biased if we do two mothers who live close together as it is not so far to walk, when only 1 name has come up on the list of 50. So only these 50 will be interviewed.

2.4. Draw up questionnaire (Each co-ordinator given a questionnaire.)

2.4.1. How the questionnaire was developed.

Drawing up the questionnaire has involved looking at other people's questionnaires, how other CBR projects have been evaluated and asking people who work in the area of primary health care for their opinions.

2.4.2. The structure of the questionnaire.

The questionnaire is divided into sections. Each section is in a different colour. The first page is yellow. This is the basic information you will need which will be filled in for you before you go to each mother. You will not have to write on the first yellow page. It will tell you the name of the mother you will be interviewing, where she lives and her child's name is. The rest of the information on this page will be used to analyse the results.

The section in pink is the questions that you have to ask. It has a number of different sections:

- A. Introduction
- B. To determine the mother's attitude to the R.W.
- C. To determine the mother's understanding of the problem with her child.
- D. To find out the mother's feelings and needs.

The questions with stars are questions in which we ask the mother her feelings about certain things. These require more than one word answers.

The page in blue at the back is observations you will need to note when you are in the house. It is not questions you will ask the mother.

2.5. Collect necessary data.

This is where you are fitting into the research process. You will go from house to house interviewing mothers and filling in the questionnaire. Other data will also be collected from the same mothers by the rehabilitation therapists.

2.6. Record data

This is where you are fitting into the research process. When you are finished interviewing the mothers, all the answers will have to be translated, as these will be recorded on a computer by someone who may not understand all the Xhosa.

2.7. Analysis

This involves putting all these results on the computer. The computer can then compare the answers to different questions and draw graphs.

2.8. Interpretation of the data

What do the results all mean? Is the R.W. project meeting its objectives or not. What other implications does it have for the project? Are the mothers of one R.W. not satisfied? Are we not meeting one of our aims?

2.9. Writing up

The process, results and interpretation all need to be written up and fed back into SACLA and to the mothers, so that we can improve our work.

3. Interviewing skills.

- * The questionnaire is in Xhosa. Write down the words the person uses in Xhosa. Before leaving the house make sure every question has been answered and filled in.

- * The R.W.s could go with you to the houses of the people to be interviewed. They would introduce you and then leave you to administer the questionnaire. They could then come back an hour or so later on and take you to the next house.

Initially the co-ordinators decided against this saying the R.W.s should go the day before and ask the mother if she was happy to partake in the evaluation by answering some questions. They would also need to ask the mother to stay at home in the morning so that the co-ordinator would find her there. The evaluation was going to be described as a method of working out if the R.W. is achieving things or is it a waste of time. The co-ordinators would be introduced as similar to the R.W.s, but C.H.Ws.

However after struggling for one day to find shacks the co-ordinators did not know, they asked if the R.W.s could do with them, introduce them and the evaluation and then come back an hour later to take them to the next house.

- * Introducing the questionnaire to the mothers/prime care-givers and making them at ease.

The co-ordinators took over the workshop at this stage. They started talking about appearance. To make the mother feel at ease it was very important to dress in a certain way. Not too smart but simply dressed, as this would make poor mothers feel ill at ease, but very neat and tidy so that people could sense a person they could trust and respect. More traditional ways of dressing should be observed as many of these mothers being squatters might be only recently from the rural areas, berets should be worn, a German print skirt, no trousers. On entering the house and sitting down, don't check the chair in case it needs a wipe.

To make the mother at ease, it would be important to take a long time with the basic introduction of yourself. Ask how she is, what clan she belongs to and where her home town is. It would also be important to focus on the children and in particular the disabled child. To draw the mother out maybe each co-ordinator should pretend she has a disabled child and describe this child and talk a bit about her problems.

- * The mother's need to be reassured that whatever they say is confidential and nothing they say will be held against them.

- * LISTEN, LISTEN, LISTEN

- * Write down the words the person uses in Xhosa.

- * There are two types of questions, straight forward ones and ones related to feelings. The questions related to feelings are marked with a star. When you come to these questions give the person time to talk, listen carefully and encourage her to talk. One word answers will not answer these questions. You may need to encourage the mother to talk a bit more.

- * Before leaving the house make sure every question has been answered and filled in.

4. Going through the questionnaire question by question.

Questions that were unclear were clarified and adjusted if necessary. Translation corrections were made.

5. Role Plays

5.1. Introductions - 2 co-ordinators acted out how to introduce yourself as the interviewer to put the mother at ease.

5.2. How not to listen - 2 co-ordinators acted out how not to listen by interrupting, finishing the sentence for the mother, jumping to conclusions, not picking up clues and chasing these.

5.3. Listening - 2 co-ordinators acted out listen well, by making the mother feel at ease, listening actively and asking probing questions to encourage the mother to talk more.

6. Interviewing each other.

7. Piloting the questionnaire.

The co-ordinators went out in pairs to interview 4 mothers with children who have poliomyelitis. They went in pairs so that the person observing could watch the mother closely to see if she really understood the questions, they could make the observations together and discuss how responses should be recorded.

8. Report back.

Problems were ironed out.